

**CALDWELL PUBLIC HEARING  
JULY 16, 2009**

**INTRODUCTORY STATEMENT**

Health and Welfare Rules

Docket Number(s):

16-0305-0902– Rules Governing Eligibility for Aid to the Aged, Blind and Disabled (AABD)

16-0318-0901- Medicaid Cost-Sharing (Fee Rule)

Hearing Date: Thursday, July 16, 2009

Location: Department of Health and Welfare  
Region III  
3402 Franklin Road, Sawtooth Room  
Caldwell, Idaho

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1           *HEIDI McDOWELL:* So let the record show that I am Heidi McDowell, designated as the  
2   Facilitator by the Administrators for the Divisions of Medicaid and Welfare in the Department of  
3   Health and Welfare. It is 5:00 p.m. on July 16<sup>th</sup>, 2009. We are in the Sawtooth Room at the Regional  
4   Office of the Department of Health and Welfare in Caldwell, Idaho, and this is the time and place set  
5   to receive oral comments, as provided for in Section 67-5222, Idaho Code, for the proposed rules in  
6   the following Dockets:

7           16-0305-0902 - Rules Governing Eligibility for Aid to the Aged, Blind and Disabled (AABD)

8           16-0318-0901-- Medicaid Cost-Sharing (Fee Rule)

9           The purpose of this proceeding is to gather the facts, views, or arguments from all interested  
10   persons relative to the proposed rules so that they may receive consideration by the Department of

1 Health and Welfare. I will accept written statements or documents at the hearing today if relevant  
2 and signed by the persons presenting them. The materials will be included as exhibits in the record,  
3 which I will transmit to the Department's Administrative Procedures Section following the closing of  
4 this hearing.

5 Let the record show that the notice of this hearing was published in the Idaho Administrative  
6 Bulletin on Wednesday, July 1<sup>st</sup>, 2009, as required by Section 67-5221, Idaho Code. This publication  
7 was timely made and other necessary notice requirements have been met.

8 As this hearing is an informal proceeding, there is no right to cross-examine a person offering  
9 a comment, nor is there a right to counsel or subpoena. No objections or procedures of a technically  
10 legal nature will be received. As the Facilitator, I am the sole regulator of the course of the  
11 presentations, including, but not limited to, a determination that the comments are outside the scope  
12 of the rule or that comments are unduly repetitious. I would like to emphasize that this hearing is  
13 being held to gather public comments on the proposed rules. It is not a forum to debate the issues  
14 involved in the rulemaking or to conduct a dialogue. This hearing time is reserved for you, the  
15 public, to provide oral comment on the rules.

16 All those interested persons attending this proceeding are asked to sign in on the roster by the  
17 entrance, indicating a desire, if any, to make an oral presentation. After a brief statement made by the  
18 Department of Health and Welfare summarizing the information upon which the proposed action is  
19 based, each person will be given an opportunity to speak at least once prior to any person being heard  
20 a second time.

21 At this time, the Department of Health and Welfare's statement will be read into the record,

1 followed by the oral presentations.

2 As part of the 2010 Medicaid appropriation (House Bill #322), the 2009 Idaho legislature  
3 gave the Department direction to establish cost-sharing based on ability to pay for families whose  
4 children are eligible for Home Care for Certain Disabled Children (commonly known as the Katie  
5 Beckett Program). The parental cost-sharing requirement will encourage families to take financial  
6 responsibility for a portion of the program cost while allowing Medicaid to focus limited resources  
7 on those families with the greatest financial need. The dockets that we will be hearing testimony  
8 and comment on are the changes to Idaho Administrative Rules to implement this cost-sharing  
9 requirement.

10 16-0305-0902 – Rules Governing Eligibility for Aid to the Aged, Blind and Disabled  
11 (AABD). These changes add the requirement for cost-sharing to the eligibility for Certain Disabled  
12 Children section of the rules, which is 16-0318-0901 – Medicaid Cost Sharing (Fee Rule).

13 These rule changes contain the amount of cost-sharing families will be required to pay to  
14 the Department, the consequences of not paying, and the authority for the Department to pursue  
15 collection of delinquent payments.

16 To begin, I will call upon persons, in order, who indicated on the roster a wish to be heard.  
17 Since these proceedings will be recorded, I ask that those who wish to make oral presentations come  
18 forward to the podium, preceding their comments with their name, spelling your surname.

19 *RENE BONNETT:* My name is Rene Bonnett, and I have a seven (7) year old son with  
20 Downs Syndrome. He just completed first grade this year and is in a typical classroom with a full-  
21 time aide. He is reading, he's writing and he is keeping up with all of the typical students in his

1 classroom, and all of this has been made possible by the services he's received with developmental  
2 therapy, speech therapy, occupational therapy, and physical therapy. We had to try to get the Katie  
3 Beckett Program three times before he was actually accepted into the program. And we do have  
4 private insurance, but the insurance companies have a lot of verbiage that make it impossible to get  
5 reimbursed or to get coverage for any sort of therapy. Our insurance will pay for speech therapy as  
6 long as it was a result of an accident. They'll pay for physical therapy as long as the diagnosis will  
7 change. His diagnosis will never change but he will improve with therapy. I don't mind paying a fair  
8 share for this program, but what the Department of Health and Welfare is saying is that they need to  
9 recover \$210,000 a year. There is 2,100 families say in this program and you charge them \$15.00 a  
10 month, you would recuperate \$378,000 a year, which is \$168,000 more than you need. Under this  
11 current guideline, I would be paying almost \$10,000 a year for my son to be able to receive services.  
12 I would go out and purchase private insurance but I can't find private insurance that will pay for  
13 therapy, and I feel like I am being made to choose between my son and affording insurance, and  
14 affording the benefit to him that therapy will provide. And I really hope that the Department of  
15 Health and Welfare will take into consideration the amount of administration costs this is going to,  
16 for the tithing scale, the amount of time this is going to take to administer this program, and consider  
17 alternatives that us as parents are willing to do. And I think all of us are willing to do something to  
18 help fund this program. Again, I thank every therapist that I have ever had in my son's life, and I  
19 don't know what I'll do without this program, but I know that I can't afford to pay \$10,000 a year for  
20 it. So, thank you.

21 *CORI DALTON:* My name is Cori Dalton, and I wanted to speak today because I have an

1 autistic child. He's three (3) years old. And I'm going to try to do this without crying. He qualified  
2 for Katie Beckett after his diagnosis. I was on the phone, you know, every other day making sure that  
3 we have this so he could get the therapy that he needed. When we got the Katie Beckett, he was able  
4 to receive developmental therapy. He just got qualified for IBI. Okay, my son was diagnosed in  
5 February. The changes he has made since February to now is amazing, but I could not have done this  
6 without Katie Beckett. I've wrote it all down, hold on. He right now receives speech, and OT, and  
7 DT, and will be getting IBI. My insurance, my private insurance that I pay for, has paid for  
8 everything besides the developmental insurance. That's it. My insurance has picked up 100%, and  
9 oh my gosh, I am so grateful for that, but when we go to pay for, you know, the cost-sharing, me and  
10 my husband are both teachers. I love my job but an extra \$250 a month is going to strap us so tight.  
11 That's food and that's gas. Would I have bought my new house had I known I had to pay premiums  
12 that were that much? Had we bought a car, had we done those things? No, I would have financially  
13 planned maybe a little bit better had I known that I would be paying \$250 to \$300 extra a month.  
14 Another therapy he receives is we do the play projects through Easter Seals, and that's \$350 a month.  
15 And without my family, I could not do this. My son would suffer because of it. And my fear, my  
16 biggest concern with cost-sharing is people are going to pull their children, you know I'm speaking as  
17 a mom of an autistic child, is they're going to pull these kids from therapy that they so desperately  
18 need to be functional. I teach in a high school and I teach, I do an adaptive P.E. class for self-  
19 contained classrooms, and one of my self-contained classrooms is an autistic classroom. I've seen  
20 kids that are older that these therapies were not available to, and I've seen what can happen in the  
21 course of six months with my child. And the fact that Health and Welfare wants me to choose to do

1 that or not scares me to death. And it will cost you more money in the long run, in my opinion. But  
2 anyway, early intervention is most important and a lot of families may have gone into debt to help  
3 their children, so we've got personal loans, we've got credit card debt. Well now they're working to  
4 pay that off and then you have to pay an extra \$250 a month to make that, to make sure that your  
5 child has that therapy, that to me is wrong, but that's just what I think. I know that we pretty much  
6 live paycheck to paycheck, and like I said \$250 is gas and food for us, you know, for a couple weeks  
7 time. We will make it work because I've seen what can happen with the therapy. But like I said, it's  
8 going to put a strain on us financially. I don't mind paying something, I don't mind that. But to be  
9 charged 4.5% of our monthly salaries is way too high, especially when I'm paying other insurance  
10 premiums. So for some families it's going to be beneficial to drop their private insurance, and then  
11 Health and Welfare is going to take it in the shorts, for better choice of words, and pay a lot more  
12 money for that therapy. Like my private insurance picks up his MRI and EEG. Next time, Health  
13 and Welfare can do that. I'll drop my private insurance. So, I mean that's just a thought. And then  
14 we're being, our premiums are based on what we make before taxes. Well, that's not what I'm living  
15 off of. I'm living off of what I bring home monthly, and then aren't we taxed again and that funds go  
16 into Medicaid somewhere else? So it's like we're being double slapped. Sorry, I'm not being very  
17 politically correct. I'm not. Here's another thing. What about the families like us that have  
18 insurance? Could there be a possibility where there's a different program set up where, you know, I'd  
19 be willing to pay for my son's healthcare, and doctor visits, and dental visits, but his developmental  
20 services, we just can't, that's way too much money for us. Right now the GT and IBI is so crucial to  
21 my son's development that we can't drop it, so my private insurance doesn't cover these therapies so

1 we have to stay with Katie Beckett. What about the families whose children don't need IBI, are they  
2 going to be expected to pay as much as we are? You know, if you're just receiving speech and you're  
3 paying \$400 a month, that just doesn't seem right. I would, that just you know does that make sense?  
4 That's not making sense to me. Again, I don't mind paying something, but it should be taken into  
5 consideration with the scenarios. I am truly worried for families that have children on the Spectrum.  
6 These kids need therapy and if people pull their kids out, then only the children will suffer. We're  
7 going to do what we have to do to ensure that our son gets what he needs. He has made so much  
8 progress since his diagnosis, but he's been immersed in therapy since then. I'm not sure what the  
9 future holds for my son, but I can tell you right now I can see the light at the end of this autistic tunnel  
10 for us because I've seen the progress he's made, but what if we have to make that choice and he can't  
11 have that service. So that worries me just a little bit. So, here's a thought, 1 in 150 kids are  
12 diagnosed with autism. For every girl diagnosed, there are five boys. If people have a concern about  
13 a child, do you really want them to hesitate to get them therapy because of how much it's going to  
14 cost them. So, I am right now just speaking about autism, but there are so many children with  
15 disabilities, and what about those families? So, please take into consideration our family needs  
16 individually. Autism is becoming an epidemic, and to make it more difficult for children to get help  
17 is a shame, and cost-sharing is just another bump in the road to get that help. So, I appreciate you  
18 letting me talk tonight. Thank you.

19 *HEIDI McDOWELL:* Richelle Tierney?

20 *PAUL TIERNEY:* My name is Paul Tierney. Tierney, T-I-E-R-N-E-Y. And I also have son  
21 that has autism. He's twelve (12), sorry, this shouldn't be that hard. And the cost of the co-pay for

1 Nicholas' Medicaid coverage will be more than the cost for our entire family under our private  
2 insurance coverage, which as the other two speakers have said, that those kinds of costs for our  
3 family are just not possible. We just can't make those type of payments. And we do have private  
4 insurance and we wouldn't be allowed to cancel the insurance. That would be, you know, an option  
5 that we all would think of. "Well, maybe I could save some money by cancelling that." But if you  
6 keep Katie Beckett and you keep Medicaid, you wouldn't be allowed to do that. You have to keep  
7 that private insurance and Medicaid would remain secondary if it's available to you. So they're not  
8 even allowing that. So you have to pay double insurance on your kid anyway whether you're getting  
9 anything out of that primary insurance, you'd be forced to keep it. And as she's said, there are many  
10 programs that aren't covered by your private insurance. That's the only way that a family can get  
11 those things is through their Medicaid coverage. Another thing is through a school, being a teacher,  
12 is talk about an adaptive program. All of those things are reimbursed back to the school through a  
13 Medicaid program. If you're kids aren't on Medicaid, those programs aren't going to be reimbursed  
14 through the Medicaid program anymore. Those are going to dry up. You're not going to get those at  
15 school. They're not going to be available in the community if you don't have Medicaid and the Katie  
16 Beckett waiver. I think everybody here is like willing, when you call it cost-sharing, I think it's  
17 disproportionately being put on the parents. It's not a cost-sharing, it's like a cost-penalty I think. A  
18 cost-sharing would be reasonable amount of \$75, \$50 per child, but \$300 to serve one individual in  
19 your family? That's very cost prohibitive for almost every family regardless of where you are in  
20 income level I think. Another thing, I was driving over here and they were talking about a cost-  
21 sharing program in Howard County, Maryland. And it was just happening on the radio while I was



1 driving over. And it's for people who are at one point 1 to 3 times the poverty level in that county in  
2 Maryland, and they had a whole lot of people sign up when this program became available. And  
3 seven months into the program they had a 70% dropout rate because parents and families in that  
4 range just couldn't afford the insurance. So to think that a family could afford \$300 to cover one  
5 individual is really not reasonable, especially in Idaho where people make less. I mean our wages are  
6 somewhat lower. Just in closing. I just wanted to say that the estimated cost that they think they'll  
7 save in the program is \$200,000 for the Medicaid program in Idaho. I think the cost to Idaho families  
8 will be much greater. I know it will be much greater than that. Thank you.

9 *HEIDI McDOWELL:* Tom?

10 *TOM BARTON:* Hi. My name's Tom Barton. I have a seventeen (17) year old son with  
11 Coffin-Lowry Syndrome. And I'm not good at talking, so. He was on Katie Beckett since he was  
12 four (4) years old and we used to pay \$50 a month, which we had no problem with, but I can't afford  
13 \$300, \$250. I don't think anybody in here can. The programs you get with Katie Beckett are just,  
14 you know, you get therapy, developmental, speech, all of that, and without that my son would, I don't  
15 know where he'd be, you know, it's helped him so much. And if I can't afford this I have to make a  
16 choice between feeding my family or having insurance on my son, and if I can't have insurance on  
17 my son then he's going to be institutionalized. And a lot of families are in the same boat, and it's  
18 going to cost the State a lot more money in that way than it is to let us pay a fee that we can afford.  
19 You know, \$15, \$50, whatever it is, but \$100 and above, I mean, a lot of families, most families can't  
20 afford that. We have car payments. We have house payments. We have to buy stuff for the kids and  
21 stuff therapy-wise, and stuff too you know, we buy extra for the kids. I mean I just don't see the point

1 of you putting us on the spot to choose between our kids, or food in our house, a roof over our heads.

2 And I just don't think that's right. That's all I've got to say.

3 *HEIDI McDOWELL:* Tresa Ball?

4 *TRESA BALL:* My name is Tresa Ball and I have a son who has Angelman Syndrome, and  
5 it's a disorder that's a genetic disorder, and he has severe limitations physically, cognitively. He's  
6 nonverbal and he will remain nonverbal. He also requires 24 by 7 care, which many of your children  
7 require as well. But our goal as a family is to be able to keep him in our home and not put him into  
8 an institution. But in order to be able to keep in him our home, the therapies and the assistance that  
9 we receive through Katie Beckett is essential. We cannot do it without it. For example, he is  
10 currently receiving IBI therapy, and as a ten (10) year old he is getting more physical, stronger than  
11 me sometimes, and if we don't modify his behaviors at this age we won't be able to keep him in our  
12 home. So these therapies are essential for many of us to be able to keep our kids in our home. So my  
13 request for Health and Welfare is to rescind this temporary rule, to come up with a task force or a  
14 team that includes the stakeholders including parents and families that can come up with an  
15 alternative that will work both for the State and for the community. Then, come up with something  
16 that's reasonable, that's affordable, and can meet the goals of all of the stakeholders. This plan  
17 doesn't do that. If participation in Katie Beckett requires excessive fees, many families including  
18 ours may be required to discontinue our private insurance and that will result in even higher costs for  
19 Medicaid for the State, and those fees may also force some families out of Katie Beckett altogether,  
20 which will result in minimizing the capabilities of those children and maybe result in  
21 institutionalization later as well. So, although some type of cost-sharing might be necessary for the

1 Katie Becket Program, I'm okay with that, but the premiums that are recommended, the 3%, the 4½%  
2 are not acceptable. They are excessive and it causes excessive burden on our families. And quite  
3 honestly, a lot of middle income families won't be able to afford it. There's simply not that extra  
4 funds available. That means that some children who are eligible for Katie Beckett will be impacted  
5 more so than others. So some will be prohibited from the opportunities to receive these services and  
6 that will be a despaired impact on those middleclass families, because the middle income families  
7 will be required to pay the excess fees but low income families will get free services for the same  
8 program, the same services for no money. And so the middle income families are being penalized  
9 through this program and being negatively impacted when they're being required to share where the  
10 low income are not being required to share. So even though the middle income families do have  
11 higher earnings, much of that income is already being used to care for our children. Many of these  
12 families in middle income also aren't eligible for any other government programs. The low income  
13 families are eligible for other government programs, so again, a despaired impact on the middle  
14 income families. In addition to the excessive premiums, the cost-sharing penalizes families like ours  
15 who make a good-faith effort to be good stewards of the Katie Beckett Program. We don't maximize  
16 every program that's available. We use good judgment in the programs that we use and we only use  
17 that that's critical. So this recommendation, it fails to consider the amount or the frequency of  
18 services that are received by families, by disabled child, so some co-pay or some other adjustment  
19 needs to be incorporated to result in those individuals who use more services pay more and those that  
20 use less pay less. Instead, it's penalizing those that are being frugal and it's going to reward those that  
21 milk the system, which is unacceptable. The recommendation also fails to consider that the reduction

1 in Medicaid cost occurs because we are willing to cover our children on our private insurance that  
2 bills primarily first. We should be able to receive a credit for cost-sharing by providing that insurance  
3 ourselves. That should be taken into consideration and accounted for. As I said, we follow these  
4 approaches and we try and be good users of the Katie Beckett Program and this cost-sharing approach  
5 is unaffordable. Another component is that I think evaluation of a cost-sharing method needs to take  
6 into consideration our cost-sharing that we are already doing as families. For example, the private  
7 insurance that I mentioned. Secondly, those things that we're not using maximums on. Prescriptions,  
8 for example, on prescriptions we pay for that ourselves and we don't bill Medicaid for that. We pay  
9 for it through our insurance and our co-pays, and that's over \$6,700 a year that we are already  
10 contributing as cost-sharing. We pay for all of our respite care that we receive personally. We pay  
11 for any travel and miscellaneous expenses. We provide the 24 by 7 care ourselves. And if we have  
12 PT or OT or speech therapy, we do consult appointments so that we can then do the therapy in our  
13 home rather than doing repetitive and excessive appointments. So for these reasons, I strongly  
14 recommend that Health and Welfare not continue with the recommendation of the 3% and the 4½%  
15 because it is excessive. A couple of alternatives that I would like to have considered I'll submit in  
16 this document, but one would be reducing the premiums. So, still looking at income base but looking  
17 at net income rather than gross income, doing a sliding scale but slide it from 1% to 2% maximum,  
18 have an annual maximum contribution per family, and spread the funds out so that we're not  
19 impacted as severely as we are now with this proposal. That still allows us to contribute but it makes  
20 it more affordable. And I again will submit this in the letter that I leave. The other approach would  
21 be to incorporate cost-sharing in the components so that it's an equivalent impact rather than

1 negatively affecting only the middle income family, provide partial cost-sharing to families that are  
2 providing insurance, require co-pays for those that are using more services than others, and use  
3 scenario-based examples as was mentioned earlier rather than across the board increase. And even  
4 another alternative would be to set maximums, just like private insurance sets a maximum number of  
5 PT appointments per year. Set up maximums, and if you get to that maximum you receive Katie  
6 Beckett and if you exceed that there might be at some point where you are required to do it private  
7 pay. From behalf of my family and potentially others of you that have disable children, we will be  
8 severely impacted by this change, and I would ask that it not proceed with the current excessive  
9 premiums, that other ideas and alternatives be considered. Thank you.

10 *HEIDI McDOWELL:* Sharlynn Traver?

11 *SHARLYNN TRAVER:* Hello. My name is Sharlynn Traver. That's T-R-A-V-E-R. I have a  
12 Downs Syndrome son who just turned eighteen (18) years old and we are in the process of changing  
13 him from the Katie Beckett Program to the Developmentally Disabled Adult Program. The past few  
14 years, the Katie Beckett Program has been a blessing to Joshua and our family. I've come today to  
15 present material on behalf of other families who need the Katie Beckett Program and for the taxpayer  
16 who wants to help, who wants the Health and Welfare system to run as efficiently as possible. It  
17 costs our family an extra \$150 a month to include Joshua on our family's health insurance plan  
18 through my husband's work. That comes to \$1,800 a year. If the proposed premiums Health and  
19 Welfare has established had been in effect last year, we could not have afforded to pay both the  
20 insurance premium and the Katie Becket premium. We would have had to drop the health insurance  
21 and let Medicaid pick up the whole tab. But because of our health insurance, we save Medicaid

1 \$908.96 of medical bills, plus greatly reduced prescription bills, plus they paid nothing on dental  
2 bills, optometrist bills, nor glasses bills. Last year was a good year for Joshua. His medical bills were  
3 only \$1,070.96. But the year before in 2007, Joshua developed pneumonia and had to be hospitalized  
4 for ten days, most of which the insurance company paid. This year hasn't started out well either. Due  
5 to an episode of unconsciousness, Joshua has had to have several expensive tests. His medical bills  
6 this year are already \$1,752. That's \$681.04 more than last year and we are only half way through the  
7 year. This year our family's gross income is down and it would be tempting to pay Medicaid \$15 and  
8 drop our health insurance. Depending on where you read, 15% to 32% of Idahoans do not have  
9 insurance. That means 68% to 85% do. The 21<sup>st</sup> of January, 2009, Ms. Clements said that 2,001  
10 children are enrolled in the Katie Beckett Program. I could not find a statement of how many of those  
11 children are also covered under their family health insurance plans. The State average would put it at  
12 1,428 to 1,785. Comparing the amount families would pay Medicaid under their cost-sharing  
13 program versus the additional costs Medicaid would spend if families were forced to give up their  
14 family's insurance is definitely a losing situation for the Idaho taxpayer. Families love their children  
15 and contribute great amounts of time, effort, and finances to help them develop to the fullest extent  
16 possible. They do the same for their developmentally challenged children but need help and guidance  
17 to know what their child needs to get past developmental hurdles a normal child (*inaudible*) on his  
18 own. Katie Beckett makes this possible. In 2003, I worked for a short time with the developmentally  
19 disabled adults who had been raised in an institution. My young son's abilities far surpassed those of  
20 these adults. The greatest benefits come for developmentally disabled children when they can be  
21 cared for by their families. This is also the best situation for the Idaho taxpayer. Don't increase the

1 Idaho taxpayer's burden by making families give up their life insurance policies. Thank you.

2 *HEIDI McDOWELL:* Roger Gibson?

3 *ROGER GIBSON:* Hello. My name is Roger Gibson. G-I-B-S-O-N. And I'm a father of  
4 two children, one has autism and one has Asperger's Syndrome. And the reason I don't, I'm against  
5 increasing the fees is I kind of have a special situation. In 1996, my wife was in a car accident and  
6 the medical expenses were \$750,000. My out-of-pocket expenses are \$250,000 in the last thirteen  
7 (13) years. I pay \$20,000 a year for her rehabilitation and stuff, just her alone. This does not count  
8 my two disabled children. And without the Katie Beckett Program, they would not have gotten as far  
9 as they did now. Currently, they will be seniors at Thomas Jefferson Charter School, and will be  
10 graduating because of the benefits of the Katie Beckett Program. If I have to pay \$200 to \$300 in  
11 addition to my \$20,000 that I pay for my wife, they would not have gotten this far. They would be  
12 basically have dropped out of school at this point because the services that we were able to get, the  
13 behavioral modification, and the medical, the prescriptions, and that type of stuff that we get through  
14 Katie Beckett allowed them to continue in school, modify their behavior, and they are doing fairly  
15 well in school with this support. I also work for the University of Idaho, and it has an interesting  
16 situation in that we are not allowed to have CHIPS or anything like that a University of Idaho  
17 employee. It's the only agency in the State we're not allowed to get State support for insurance, and  
18 so Katie Beckett was able to help us along that line. The other thing is that Katie Beckett premiums  
19 are based upon gross income. When you take \$20,000 of my income, take home income, my net  
20 income that I have to pay my mortgage and other expenses for quite a few years is running at  
21 \$12,000. I still drive a 1992 Plymouth Grand Voyager because I chose to use that money for my

1 children's expenses and to help rehabilitate my wife. If they raise my premiums because of my gross  
2 income to \$300 or so, I would not, if I was starting on Katie Beckett, not have the opportunity to put  
3 the kids through these programs. I also work in the prison ministry. A lot of the guys I work with  
4 have developmental disabilities and did not have the Katie Beckett Program or the support at home. I  
5 think if you have parents here who are going to have to drop the Katie Beckett Program because of  
6 these high premiums, you are going to have a lot more in the court system. They're going to get their  
7 drugs on the street, and then you're going to have their kid in the welfare system under Medicaid. So  
8 I think personally it's a short-term fix that's going to cause a long-term problem in the system. We're  
9 going to have thousands of kids join the system in the next ten to fifteen years, I think, if this fee  
10 schedule go through. I thank you.

11 *HEIDI McDOWELL:* Betty Reynolds?

12 *BETTY REYNOLDS:* Hi. I'm Betty Reynolds and I have an eight (8) year old son with  
13 Downs Syndrome, and I've been fortunate. We've been lucky and blessed because his health issues  
14 have been nothing. He wears glasses, he has tubes in his ears, and that's it. But if it wasn't for the  
15 speech and OT therapies that he was getting outside of school, he wouldn't be the little boy he is now.  
16 He's very, you can understand him, he's very personable, he's getting along fine in school and in his  
17 community, but I had to leave speech therapy for a while because it wasn't working out at one place;  
18 but we found another speech therapist and a program that really has worked for him, and in the last  
19 six months his speech has just blossomed, and it's just a delight to have him and to be his mother. So  
20 I feel very fortunate. But I also work in the school system as a paraprofessional in a Special Ed.  
21 Preschool. And so I see little ones that come in to us having no services and their parents are naïve to



1 what's out there, and having the opportunity to introduce them to what they can have, what's  
2 available, and encouraging them to help their children get services, and just the difference in which  
3 we've seen in kids in just a short period of time getting the extra services. So it's so, so important,  
4 and you guys know that, and I admire everyone here all you parents of kids, parents that have kids  
5 with special needs, because it's a wonderful blessing but it's also very heart retching, and we would  
6 do anything and everything for our children. But my understanding when we came into Katie  
7 Beckett, because we got denied by Medicaid and we got denied by everybody, but when I came into  
8 Katie Beckett it wasn't determined upon my income and what I made. So now, my son is going to  
9 get penalized because my husband has a good job and we make an acceptable amount of money, but  
10 it's going to cost a lot more for us to have him in Katie Beckett than it would to have his services  
11 outside. And so I just think they need to come up with something, a win-win situation, so that we  
12 can. We have the best interest of our kids in mind. They need to have the best interest, because  
13 Special Ed., people with disabilities, are a minority, and we feel, my husband and I feel like there's no  
14 one out there who really gives a darn about them and who is going to even try to help them. And so,  
15 hopefully this will help, as parents pulling together and letting them know how we feel, because we  
16 do need the services. We need the Katie Beckett. We need it for our own sanity, but we also need it  
17 for our little people, because we want them to grow up to be big people who can cope in this world as  
18 much as they can. And I learned from the time he was a baby that I'm his greatest advocate, and if I  
19 don't do something, if I don't speak up, he's going to get walked all over and no one's going to help  
20 him at all. And so, I just hope that this is going to help and that they can come together with  
21 something, because I too is willing to pay but it's going to be more that we have to pay privately, and

1 there's got to be a better way, and so that we can help our children and that we can help each other,  
2 and that these kids can get the best because they deserve it. It wasn't their fault that they came to  
3 earth the way they did, but we're here to help them so that they can have the best life and best  
4 experience here that we can make possible because we love our kids. Thank you.

5 *HEIDI McDOWELL:* Dave Thompson?

6 *DAVE THOMPSON:* Hi. My name is Dave Thompson. T-H-O-M-P-S-O-N. And I, like  
7 Mr. Gibson, drive a 1992 Plymouth Voyager, and I know what he's going through. We received a  
8 letter in the mail, as I believe most of us in this room did, a few weeks ago telling us that we were  
9 going to need to pay something termed insurance in order to retain our Katie Beckett benefits. And  
10 we were shocked when we saw this. We studied it, we thought about it, we talked to dozens and  
11 dozens of people, especially my wife, and learned a lot about what this might mean to ourselves, to  
12 the children involved, and to the community. Because of what we've learned and what we thought  
13 since then, we are very much opposed to the proposal that we received in the mail for a number of  
14 reasons, many of them have been stated tonight and we certainly support those. A couple of things I  
15 will add that might provide a little different twist to it. I personally do not look at this as an insurance  
16 premium. Insurance premiums are very seldomly, if ever, based on income. They are based on  
17 services. I already pay income tax. I already pay Medicaid to the Federal and to the State  
18 government, and to be asked to pay 3 to 4.5% additional monies to support a plan that we're already  
19 paying for and that is a service peculiar to our family but every family in the country has services that  
20 are peculiar to them that come out of their taxes, that are paid by their taxes. I don't feel that this is a  
21 fair approach to how we should fund this program. In affect, I believe that this is an income tax

1 targeted at families with disabled children. I believe the use of the term “insurance” is a euphemism  
2 for income tax that is not politically acceptable and that if the politicians who want this to happen or  
3 the people in Health and Welfare want this to happen, a term is a tax, this would never have gone  
4 through and they would have many more people that are in this room tonight angry about what is  
5 happening. I understand that the cost of supporting our children, these disabled children that we have  
6 is expensive. It costs millions of dollars every year. The target that we are trying to achieve here,  
7 from what I understand from my reading of the billing and some of the supportive documentation  
8 behind it, is a savings of about \$210,000. We’ve heard that figure a number of times. If we have  
9 2,100 people in the system and we save \$210,000, that’s about \$100 a family we’re trying to save. I  
10 guarantee you that if we go through with this program, that as people roll over from personal  
11 insurance to more dependence on Katie Beckett Medicaid insurance, as these kids whose families  
12 have tried to get out of Katie Beckett because they can’t afford it, their kids will experience more  
13 problems within their families, within society, we’re going to be spending millions and millions and  
14 millions of more dollars annually trying to resolve all the problems this will cause than the \$210,000  
15 this is targeted to save the State of Idaho. It’s way, way out of line. And I do believe that we do need  
16 to help, but 3% to 4.5% is just very excessive and it’s going to harm a lot of families, it’s going to  
17 harm a lot of kids, and it’s going to harm our society. A couple of other things, well actually, you  
18 guys have already made those points. I do want to just reiterate a couple of them briefly because  
19 they’ve already been stated so well. We are in difficult economic times. Families are going to have  
20 to make a choice. Some families will choose to stick with the plan and pay what I believe are excess  
21 fees. Some families are going to drop out and those kids are going to get hurt. Some families will

1 stop their insurance, their personal insurance, and rely more heavily on Medicaid. That's probably  
2 what we will do. We are already carrying some burdens. We could transfer over to Medicaid if we  
3 wanted to from our personal insurance. Those expenses are again going to cost the Idaho taxpayer  
4 millions and millions and millions of dollars, and there's no way we're going to save anything.  
5 We're certainly not going to save \$210,000. We're going to cost Idaho taxpayers millions of dollars  
6 for this plan. And again, we'll hurt our children. And that's what I have to say. Thank you.

7 *HEIDI McDOWELL:* Sue Thompson?

8 *SUE THOMPSON:* My name is Susan Thompson. T-H-O-M-P-S-O-N. We have a son on  
9 the Autism Spectrum. My husband drives that old car because when I got pregnant with my son I  
10 also got Stage 4 colon cancer at the same time. I'm trying very hard to keep this together and I'm not  
11 going to do well so it will probably be short. So we have spent over the last several years every spare  
12 penny we have paying the extra money we have to pay off colon cancer bills. We still have at least  
13 3½ more years in our plan to get those bills paid. Add on top the extra things that we've put our son  
14 in that aren't covered by Katie Beckett because there are things out there. I mean, we've all tried  
15 everything, you know. (*Inaudible*) diet, you know, this doctor here, that doctor there, manipulation of  
16 the skull. Haven't done that one but I've heard many people have. So besides what Medicaid has  
17 paid for we have put out quite a few dollars that have been very useful in some cases and not very  
18 useful in other cases. Without Katie Beckett I wouldn't have been able to take my son to the grocery  
19 store. I'd push him down the grocery store and he could sit and hit people ten feet away from us. He  
20 could paint his room in poop in 20 minutes of not being watched when he was two (2) years old. IBI  
21 has made our lives livable, made his life livable. It's given the possibility that our son may grow up

1 and be able to at some time in his life live on his own and hopefully be a productive member of  
2 society. Without the interventions we have gotten and without skills that we have learned, we never  
3 would have been able to do that on our own. And so we're grateful for Katie Beckett. But, they're  
4 looking at my gross income. My gross income looks pretty good. If you look at how my house is  
5 flipped upside down because we paid off medical bills so I could go in for another colon cancer  
6 operation when it spread to another part of my body, and then another operation after that, you'd see  
7 we have no savings left. We don't take the newspaper anymore because we can't afford the  
8 newspaper. We're down to one garbage can now because that was another place we could cut. I cut  
9 all my children's hair and I cut my own hair. It doesn't look great but hey. We have food on our  
10 table. If we are taxed at 4.5%, we are going to be making a choice between do we lose our home?  
11 Do we lose the food on our table? We've already cut back on own medications in our home or how  
12 often we go to see the doctor because when we have to pay our \$45 co-pay that's pretty expensive, so  
13 if we can put that off, we do it. I sure don't want to have to make that choice to my son, and I don't  
14 want to see other people whose children have disabilities have to make that choice for their children,  
15 because early intervention is the name of the game with all of our kids, whether they're on the  
16 Spectrum. (*END TAPE 1, SIDE A*).

17 DAYNA SANNA: I'm Dayna Sanna, and I'm a grandmother of a disabled child. I'm just here  
18 to support all of these families. And I just ask Health and Welfare to please reconsider this. I feel to  
19 have something dropped on these people out of the blue, they're not prepared. I just want to ask them  
20 to reconsider and listen to these people and find a better plan. I know the stress of taking care of  
21 these children and then to have financial burden added on unexpectedly. There's got to be another

1 way. And I'm going to make it short so that some other people can give their testimony. Thank you.

2 *PETRA SIMPSON:* I'm Petra Simpson. S-I-M-P-S-O-N. I too am going to start with crying,  
3 but I appreciate all that has been said. Everything that has been said I agree with. I have a one (1)  
4 year old daughter, and we had never planned to have a child who would have special needs. She has  
5 become a medical mystery. Doctors can't figure out why her system won't work. She doesn't really  
6 have an immune system. She can't eat. Everything is through a feeding tube in her intestines  
7 because her stomach is very abnormal. But I cannot tell you how much this Katie Beckett Program  
8 has eased our burden. She is receiving speech therapy and physical therapy because she's spent  
9 almost half of her life in a hospital fighting for her life. We are self-employed. Our cost of our health  
10 insurance is \$800 a month. Right now my husband's a plumber and we are just struggling for work  
11 and trying to keep our heads above water. We're fighting to keep our home, and we too could qualify  
12 for the Medicaid Program but we're trying to do everything on our own. My husband's out trying to  
13 find jobs. I am a stay-at-home mom because I feel like I'm the only one that can take care of my  
14 child. But I too am thinking that I might need to go find work and then pass my child on to someone  
15 else and worry about her. I feel like we are contributing by paying our gas to go to doctors  
16 appointments and we are contributing in a lot of other ways, and also the stress of having a child that  
17 needs help. I too would be willing to pay a reasonable premium, but I feel we are already  
18 contributing. I thank you for listening to what I have to say.

19 *HEIDI McDOWELL:* Lauralee Newby?

20 *LAURALEE NEWBY:* Hi. My name is Lauralee Newby. N-E-W-B-Y. And I'm here  
21 because I'm also a parent of an autistic son and he is actually five (5), but it took a while for him to

1 get diagnosed because he was a premature baby, and so everyone kept saying it was because he had  
2 been premature. And so, I've been in the system for about a year, and with Katie Beckett it has been  
3 a lifesaver as far as being able to put the hours that we do use being able to afford those services that  
4 he gets. My husband is a State worker and Mr. Recorderman. We know that he has been forced to  
5 take furloughs and decreased pay, and being a State worker. And I have had to go work part-time as a  
6 nurse to help pay for services that Medicaid doesn't cover because there are a lot of programs out  
7 there that they don't cover that are worth it that you have to privately pay for. We're just middle class  
8 people. We have insurance. And even after all the insurance adjustments and the payment, Medicaid  
9 only picks up less than half of what they're billed for services. We only use two hours a week.  
10 That's for one hour of speech, one hour of OT. And I feel that being penalized to pay the same  
11 amount every month regardless of how much you use it, and even if you don't even use it that month,  
12 you're still required to pay. That premium would definitely be a burden on us. I honestly, I don't  
13 know if we would be able to afford it. Ultimately, if we had to take him off Katie Beckett, it would  
14 be just a bigger burden on the schools because the children wouldn't be able to get their individual  
15 therapies. It would be a bigger burden on the elementary schools. Or, if you are forced to pay a full  
16 premium amount every month, then I will be darned that I will find a way to use all twenty-two hours  
17 then every week, because I'm going to get my money's worth then. So in the long run, that would  
18 end up causing them to pay for more services. A couple of things that I thought about was perhaps  
19 not basing it on the Federal poverty guidelines but increasing the income levels, decreasing the  
20 percentages, putting a cap on that percentage, a co-pay for services basically paying for what you use  
21 like you do for a doctor visit. With private insurance it's usually \$20. Basically for us, our family

1 would be squeezed and we would have to make a choice. I think it's been mentioned that you can't  
2 just completely drop your private insurance and go on Medicaid. They were saying that that's  
3 probably not an option, but it would definitely, basically it would require me to work more, be away  
4 from my son and my family more. So thank you. That's all I have to say.

5 *HEIDI McDOWELL:* Fran Self?

6 *FRAN SELF:* I hate to turn my back on people. My name is Fran Self. That's S-E-L-F. I'm  
7 the grandmother of a little boy with Asperger's Syndrome, ADHD, and I also am an IBI professional,  
8 and I've been in this field since 1981 in many different states. And I think to get back to basics, first  
9 of all the purpose of Katie Beckett to start with was based upon not because the people in government  
10 are so generous that they just wanted to open the doors to more families and had money to blow, it  
11 was because endless amounts of accounting, and research, and documentation had shown  
12 unequivocally that it would be much, much less expensive to empower middle class families to  
13 maintain their children and provide for their needs in their home versus institutionalizing them. The  
14 premise of this, and regardless of what it's called, I agree totally, it's a euphemism for a backhanded,  
15 sneaky, discriminatory tax against a small segment of the population. Again, middle class America  
16 with handicapped children who are already be taxed for this same service. The service has been  
17 already significantly cut so we're going to be paying more for less essentially, from 30 hours  
18 maximum down to 22. But getting back to the cost effectiveness, as several people have mentioned,  
19 families will have the option to institutionalize their children, which there's no question that this will  
20 be hugely more expensive. The other purpose for the Katie Beckett, and it's called other things in  
21 other states, but for this type of program, the reason why Medicaid was willing to pay for it to start



1 with was because the purpose was also to further empower families to provide therapies and support  
2 for their children that would maximize the possibility that these children would become self-  
3 supporting, at least to some extent. So if those services are financially unavailable to these families,  
4 then it's going to impact that child's expense for the community long-term, and we know from  
5 endless studies, 35 years of research, unequivocally it has been various figures have been generated  
6 but the bottom line is that for every dollar that is spent by government on prevention and remediation  
7 programs early in life for these folks with disabilities, governments save a minimum of \$7.00 in long-  
8 term costs. This has never been, it hasn't been debated, it's been acknowledged at every level of  
9 government in every state for years. So, the other thing is that this is not something new, this co-pay  
10 or tax or whatever you want to call it, it's been tried before and failed. It adds an entire administrative  
11 layer. Who's going to generate the bills? Who's going to hire lawyers to take people to court when  
12 they don't pay? In a previous life when people used to have to pay co-pays for early intervention, for  
13 example, only 50% of people ever paid. The State spent huge amounts of money trying to go to  
14 collections with folks, paying legal fees, even postage, that 44 cents a letter now. You know, the  
15 administrative, how this is going to work administratively is it's going to be a nightmare, and it's  
16 going to end up costing so much more that it will end up as usual, costing us. And I also agree  
17 completely that it's ludicrous to base it on gross income. There's nothing that justifies that. We're  
18 paying for a Medicaid funded service. It needs to be, the eligibility and any co-pay needs to be based  
19 upon the same guidelines that are used to determine eligibility, which should be adjusted income, and  
20 people should be given credit for their private insurance premiums that they're already paying. When  
21 you look at the impact on the community, we know we're in economic hard times. You start taking

1 \$200, and \$300, and \$400 a month away from people, disposable income, it's going to impact every  
2 business. It's going to impact the businesses income taxes that they pay. So across the board the big  
3 picture is it's going to be a financial disaster. The other thing that may or may not have been thought  
4 about by the State is the fact that I hope that this would be a tax-deductible expense, which again is  
5 going to lower the amount of income tax collected. So where's the advantage? Thank you.

6 *HEIDI McDOWELL:* Susie Depew-Scarelli?

7 *SUSIE DEPEW-SCARELLI:* I'm going to keep it short because I feel that there are a lot of  
8 families in this room that have very important things that they would like to share. I'm here from  
9 Idaho Parents Unlimited and the last couple of weeks I have taken I don't know how many calls from  
10 parents just devastated by what this was going to do to their families. The very first call that I took on  
11 this was a mom in tears because she felt her only alternative was going to be to institutionalize her  
12 child. And that is just not acceptable. It's just not. So I wanted to share a couple of things with you,  
13 and one of those is I was at a meeting just yesterday with someone from Medicaid, and they assured  
14 us that if you were not able to pay these fees that your child would not lose services. Okay, cool, but  
15 they added they would be taking you to collection and taking you to court to go after those fees. You  
16 know, I just really had a tough time with that, and I would like to ask all of you to join with us. Come  
17 talk to me afterwards. We are assembling letters from families that we are going to put together to  
18 help fight this and we need your help. If we all work together, let's hope that we can get this stopped  
19 because it's wrong.

20 *HEIDI McDOWELL:* Angela Lindig?

21 *ANGELA LINDIG:* Hi. I'm Angela Lindig. L-I-N-D-I-G. And I don't want to repeat a lot of

1 what's already been said which is pretty much in my letter that I've written, so I'm just going to try to  
2 break away some of it. I did want to say that I am a parent of three children, two of which have  
3 disabilities. My oldest daughter has a developmental disability called Rhett's Syndrome. My  
4 youngest daughter has Bipolar, Reactive Attachment Disorder, ADHD, General Anxiety, and  
5 Psychosis. I'm also the chair of the State Independent Living Council and I serve parents' interests.  
6 So I'm here on that behalf as well. I wrote a letter to the Governor, as well as all of the Idaho  
7 Legislators this past December to express my concerns regarding the cuts in therapy hours that most  
8 of us experienced. And I want to quote what the Governor said at that time. In response he said, "I  
9 understand how difficult those cuts are and I understand the impact that that has on the families. But  
10 I don't want to get to a point a year from now where I have to cut thirty hours – so if I cut the eight  
11 hours now and make the adjustment now, and get rid of some of the nice things that aren't necessary  
12 then I hope – I pray that the 8 hours is all that we will have to reduce for those children." We haven't  
13 gone a year and now we're being charged for the remaining services as families, and we're being  
14 charged obviously exorbitant fees, that we all agree 3 and 4½% are way too high. My own personal  
15 story, my oldest daughter does qualify for Katie Beckett Medicaid and has had that since she was  
16 three (3) years old, and like all of you, she wouldn't be the person she is today without it. So, I'm  
17 unbelievably grateful for it. My youngest daughter qualifies for mental health services based on her  
18 diagnoses, but mental health services in Idaho are on a sliding scale. My husband's income allows  
19 the slide for us to be 100%. We're responsible for 100% of the cost. So, that means that we've had  
20 to pick up where we can for her care. She wasn't getting the support that she needed in school so I  
21 wound up pulling her out of school for the last year and a half and have been homeschooling her,

1 doing makeshift therapy on my own, just doing what I can to get her everything she needs. And I'll  
2 be honest with you, when I got the letter Sunday night after the 4<sup>th</sup> of July at 10:00 at night when I  
3 foolishly checked my mail, I kind of burst into tears and said, "What are we going to do? I don't  
4 know what we're going to do at this point." So, in addition to those diagnoses, she also has been  
5 recently diagnosed with Spinal Bifida and went through spinal cord surgery two months ago totaling  
6 \$41,000. So, that same piece of paper that says that my husband makes so much money that we can  
7 afford 100% of her cost is now saying that we can afford 4½% of my other daughter's expenses, and I  
8 have to admit that really we can't. So, we're going to have to make choices, and I honestly don't  
9 know how to make those choices. I don't know where to begin to make those choices. In addition to  
10 this, in my own personal story, in addition to that and what's been mentioned here, the schools, for  
11 those families who do end up dropping out of the Medicaid systems, the schools are still required to  
12 provide the services to the children under IDEA, and now they're not going to get the Federal  
13 reimbursement on that. So it will still cost the schools, it will still cost the State, and that 's going to  
14 come from somewhere, and ultimately that's going to cost the children in the classrooms who do not  
15 have disabilities, there's a trickle down effect there on of where those expenses will be covered. And  
16 then a final thing that I want to say on this, as far as institutionalization goes, families who place their  
17 children in group homes or institutionalized care, are not charged these premiums. Their income  
18 levels don't matter. So in some cases this will be an incentive where families are on the fringe, where  
19 they're struggling to keep their kids at home as it is, if they're now going to be charged \$200, \$300,  
20 \$400 a month to keep their kids at home, there's an incentive now to place them outside of the home.  
21 And then again, now you're looking at 3 times the cost to the state. So, that's all I have to say.

1 Thank you.

2 *HEIDI McDOWELL:* Kristin Cook?

3 *KRISTIN COOK:* Hi. My name is Kristin Cook. C-O-O-K. I have a son who is three (3)  
4 years old. He has Autism. I'm here today because I just believe that this is completely unfair to our  
5 children and you other parents, like myself. When I got the letter I tried to say, "Okay, you know  
6 what, let's figure out a budget. Maybe there's some way that I can afford this." And I just can't. I  
7 can't do it. And I thought, "Well you know what, if I could cut back on the grocery bill I could afford  
8 this. So you know what, maybe I'll just file for food stamps and then I can pay for this Medicaid."  
9 But that's just the State paying me again. Or, option two, maybe I could just file Social Security for  
10 Ashton. But again, that's another burden I feel like I am on the State. You know, I don't want to be a  
11 burden to the State. So, but I don't know what else to do. I have another child. He's a toddler. He's  
12 in daycare. I can't cut that bill. That's very expensive and I cannot cut that bill. I work days, my  
13 husband works nights. If I don't take him to daycare, my husband will get three hours of sleep a  
14 night. I can't leave him with my husband with three hours of sleep. That's fifteen hours of sleep a  
15 week. Okay, that's dangerous. I can't do it, for his health and for my toddler. So, Ashton now goes  
16 to Ready, Set, Go Preschool and those people are a saint. Ashton has done so much. A year ago he  
17 didn't even say anything and now he's saying sentences. So, I'm just here because I don't know what  
18 to do. I cannot afford this and I do not want to take him out of school. And so, I just don't want to be  
19 a burden to the State by filing for Food Stamps for Social Security. Thank you for your time.

20 *JEREMY EVANS:* Hi. My name is Jeremy Evans. E-V-A-N-S. And I'll talk quickly. Our  
21 family is maybe a little bit different. We're not facing institutionalization. We have three boys, one

1 on the way, and our eldest has been diagnosed with Autism Spectrum Disorder, and I think though  
2 our story maybe is an example of why the Katie Beckett Program is so important, especially in early  
3 diagnosis and early treatment. When my son was first, we first started noticing maybe something was  
4 wrong, we were living out of state, we took him to the doctor, they couldn't quite determine anything,  
5 and they wanted us to pay a few hundred dollars to have him come back and sit for hours and have  
6 them watch him, and there were just these really expensive costs for something that we couldn't  
7 really decide was serious or not. And it wasn't until we moved to Idaho, that with the Katie Beckett  
8 Program we were able to get him into a program where people knew what they were talking about,  
9 they said, "Yes, this is on the Autism Spectrum," and we were able to try a series of different  
10 therapies: speech therapy, occupational therapy, vocation therapy. And that, combined with our own  
11 efforts, you know we were able to find some very specific therapies for my son. What I'm concerned  
12 about is now, well, I mean my situation, I'm fortunate. I have a decent job. Our son doesn't need that  
13 many therapies. So, we've looked at the numbers and it doesn't make sense for us to pay that much.  
14 We're going to figure out how to pay for the therapies that we think he needs and pick up the balance  
15 ourselves. So, I'm worried about two things. First of all, what about my neighbors kids now?  
16 They're not going to have that advantage of having a program where they can find out what's wrong  
17 with their kid, to find out if there's some therapy to help him integrate with society better. They're  
18 gong to have that, you know there's this huge incentive to deny that there is anything wrong with your  
19 kid, and you already want to resist that as much as possible, and saying, "Oh by the way, to try all  
20 these programs you're going to have to pay 3, 4% of your income." A lot of families are just going to  
21 shut down and not want to deal with that. So you're going to end up with a lot more undiagnosed

1 people, especially in, you know, any kind of borderline case. And the second thing, and I think it's  
2 been said quite a bit, if we were going to pay for it, we would make sure, we'd make darned sure we  
3 got our money's worth out of it. We wouldn't, you know, just shoot for a couple programs. We  
4 would, you know, take him for as many hours as we get every week. We would try every little thing  
5 for every incremental bit of change. Whereas now, we've really felt like, "You know there's some  
6 options out there, let's try them." And so my thought is you really need to rethink this. The income  
7 base flat fee premium approach doesn't work. We already know as a country, healthcare doesn't  
8 work when it's flat fee. The HMOs don't work. None of these things work where you pay a flat fee  
9 and what you use has no impact on what you pay. It doesn't work. Everybody's going bankruptcy  
10 doing that. So why are we going to start doing that now on the Katie Beckett Program? So, you  
11 know, figure out something so that people can maybe try different therapies at lower costs and you  
12 know maybe build up to where they're paying or pay for something for what they're using. We  
13 would consider that. But it has to be rational. I don't know who thinks that people are just going to  
14 start forking over money to use a few services a month and now it's going to somehow subsidize all  
15 of this administration and whatever else they want to do with this. It's just not going to happen. It's  
16 going to cause problems. So I hope the Committee rescinds this temporary rule. They should think it  
17 over. They should try again. You know, you reap what you sow, and Idaho will certainly reap the  
18 whirlwind if they go forward with this program. Thank you.

19 *MAUREEN EVANS:* Hi. As he said, our eight (8) year old son has autism, and I just wanted  
20 to share one little part about our, you know, seeing as the other lady said, I got home from 4<sup>th</sup> of July  
21 vacation, opened the letter, and I looked on the date on it. I think they mailed it June 27<sup>th</sup> saying it

1 was supposed to start July 1<sup>st</sup>, which was already after I had opened the letter, and that we had to start  
2 paying in October. I immediately, you know, got on the phone with all of our therapists and our  
3 private insurance, and our private insurance covers very little. It was maxed out after about three or  
4 four months in the year. And so, now we're going to have to drop from the Katie Beckett because we  
5 can't afford to pay the premium that they they're asking. So as of I guess, whenever we have to drop  
6 it, October 1<sup>st</sup>, he's going to have no coverage for the rest of the year because our private insurance is  
7 maxed out and we can't stay on Katie Beckett. So, I just feel like they didn't give us any warning.  
8 They didn't give us any time to even think about budgeting for this even if we could afford it. It's  
9 just, most people you know, we're on budgets. We're very tight. We can't just fork out \$300, \$400 a  
10 month for what this program is. And like all of you, it's changed our son's life and I know he can be  
11 a functioning person later down the road. It's given us hope, this program. And I feel hopeless again,  
12 that I don't know what's going to happen to our son because I don't know how we're going to afford  
13 any of these programs. Thank you.

14 *HEIDI McDOWELL:* Chris Casteel?

15 *CHRIS CASTEEL:* I'd like a list of all the hands in here of all the people that have a disabled  
16 child or know of someone that has a disabled child. I'd like a list of the hands of those that have been  
17 blessed by Katie Beckett. I'd like a list of those who think the government wastes money to spend, to  
18 budget elsewhere besides cutting back Katie Beckett. (*Inaudible*) voices to heard, ladies and  
19 gentlemen. I work for the Federal government. My name is Chris Casteel. Just for the record, they  
20 probably know about that anyway. I don't care. I'm able to say what I want and that's fine because I  
21 live in America. And I can tell you, I'm a parent of my kids and my youngest has Autism. And the



1 true story behind Robert, my son has Autism, is when he was three (3) years old we didn't know what  
2 was wrong with him. I was living in Twin Falls, went to Salt Lake City to see an expert who said,  
3 "Your son has Autism. Get used to him being in a group home." That trip back was the hardest trip  
4 in my life with my wife. (*Inaudible*) there's got to be something. And because of (*inaudible*), early  
5 intervention, and Katie Beckett, our son now communicates on a communicator. He knows what he  
6 wants. He gets dressed by himself. He even can cook a little bit. He bathes. He knows how to do  
7 things in life. Early intervention is the key to this. If Katie Beckett was not around, then they don't  
8 have the early intervention want those years. And what happens? Institutionalization, as we  
9 mentioned before. That costs more money. I'm going to write down some stuff and send them in.  
10 I've got a lot of figures, including on the tax rates right there. Right? Not only is it not insurance,  
11 they lose the money for income tax, but it could be pre-taxed and they don't pay any (*inaudible*) tax  
12 on it either. So that's another area that's gone bye-bye. Another thing it's going to lead to besides  
13 that is, it might not happen some places but there's some people on the verge of, "What do we do?"  
14 Some couples may get divorced. Send the child to the parent with the lower income. (*Inaudible...*)  
15 benefit? (*Inaudible...*) SSI. Isn't that great the way the government works sometimes. It ticks me  
16 off. I'm sorry. Another thing is, this gross income thing is the problem. Even though I'm an  
17 employee, we also have our own business. I fact we just started up a home healthcare business  
18 ourselves. And seeing some of the help that these people need. So slap the self-employed people.  
19 Gross income. If I'm hearing what I'm thinking, I'm going to look at it, but if it's right and it's gross  
20 income, that means a self-employed person who makes \$100,000 but spends \$75,000 expenses and  
21 takes \$25,000 is taxed on that \$100,000. That's wrong. So it's time that we stand up, make our

1 voices heard. Write things down, send them in, so they can make a decision what's right for our kids.  
2 Katie Beckett is meant to help kids, to help families. That's the main thing. The families should  
3 come first. Have your kids at home. And I know Robert's been a blessing in our home and I could  
4 not imagine him being in an institution. He has blessed us and he's blessed our other kids. And I  
5 hate to see the point where people have to go to an institution because they can't afford it. And they  
6 can't, they need that. Families need that. And the second thought is higher expenses doing it the  
7 other way around. It's been testified before. So the government can look at that. If they're not so  
8 concerned with families, they'll look at the bottom line figure. It's more expensive doing what  
9 they're doing. But I just had to leave that with you. Thank you. (*END TAPE 1, SIDE B*)

10 *ERIC ADAMS:* My name is Eric Adams. Last name, A-D-A-M-S. I've got a prepared  
11 statement here but I'm not going to read it because everybody's pretty much said everything I was  
12 going to say. So, our son has Autism. He's five (5) years old. He's in Ready-Set-Go. And we just  
13 want the Committee to consider this not to be on gross income. My wife and I are working a total of  
14 three jobs so we can have good insurance, and that's not considered in this. So, that's all I have to  
15 say. Thanks.

16 *KRISTA GROSS:* Hello. My name is Krista Gross. I have a nine and one-half (9½) year old  
17 son on the Autism Spectrum with several other diagnose issues. I've raised my son for eight years  
18 and I've been running the show by myself. His father abandoned him at birth. And I also spent eight  
19 years of active duty in the military. So I kind of figure that putting my life on the line for eight years  
20 might come back to me and help me out with my son, but apparently that's not the case. I now work  
21 as a receptionist for an orthodontist. I received a letter in the mail from the Department of Health and

1 Welfare, and it's pretty much like receiving a pink slip from my job because basically all of the  
2 income that I receive from my job is going to go to supporting my son's disabilities. The difference  
3 between, I'm now married, and the difference between my son who went through the early childhood  
4 intervention and my step-daughter who's eighteen, who we're now looking at group homes for her, is  
5 that my son has hope in his life or did have hope. He has the ability to be able to go out and make  
6 something of his life rather than being stuck in a group home. And unfortunately, when I was  
7 speaking to one of the developmental agencies, they were speaking to me about when you have to re-  
8 enroll for Medicaid in the fall, they ask you a question as, "Are you able to, if home care was not  
9 available, would they need to be institutionalized?" Unfortunately, the prison system is what's  
10 thrown into our institutionalized issues. There's so many prisoners in there because they have mental  
11 health issues and they get in trouble with the law. My step-daughter is now facing that. I have also  
12 known a parolee that served five years of meth manufacturing in prison, and she has a condition for  
13 parole now that she is to obtain a 3.5 GPA at an accredited college. She now has a Masters in  
14 Psychology. Unfortunately, now there's going to be cutbacks and where are we going to be able to  
15 get all the services that are required to help these kids grow up. What's going to happen in ten years  
16 now where all these kids are young now with the developmental issues are going to grow up and  
17 what's society going to be like then? So hopefully, Governor Otter will realize eventually what's  
18 going to happen, and unfortunately he'll be out of office by then and we'll pass it on to the next  
19 person. Thank you.

20 *HEIDI McDOWELL:* Lyle Bayley?

21 *LYLE BAYLEY:* Did you say Lyle Bayley?

1           *HEIDI McDOWELL:* Yes.

2           *LYLE BAYLEY:* I won't take very long. My name is Lyle Bayley and I want to talk about  
3 school first of all because I'm a high school principal. And for someone who might be listening on  
4 this tape recorder, this thing is going to affect the normal kids, what they would consider normal. My  
5 school offers 57 concurrent credit courses for our kids that want to go to college. They can get  
6 college credit while going to high school. Those things aren't going to be able to be offered to them  
7 because the Federal law for students, or some like mine, we have to as a school provide them  
8 services, so if we're not able to have Medicaid fund that, you know, that takes away other teachers.  
9 So, for anybody at the other end of this tape recorder who might have a child. Obviously, whoever's  
10 at the end of this doesn't have a child like we do. That's why I'm talking about normal kids, and I  
11 don't want to offend anyone in this room because you guys are quite incredible. This is a tax. I pay  
12 my taxes. For our family, \$600 a month. And it's relative to all of you on their sliding scale. I mean,  
13 it's just we make a little more so it's \$600. I've busted my ass through college. I think the letter was  
14 absolute chicken crap. And the reason it was is because no one signed their name to that. The  
15 Department of Health and Welfare. Who the hell is that? Who is that? Who do we respond to? It's  
16 not a question and answer, so who do we respond to? In my job I'm politically correct. I'm not  
17 working today. And I know in my district we raise taxes to not lose teachers this year. And when we  
18 had an open forum, we were there to face the people that were going to have to pay more for those  
19 services not to be decreased. Where are the people? Who is this on the end of the recorder? How  
20 are we to be assured that they hear this? And tongue in cheek, I think the term Health and Welfare is  
21 kind of ironic because they are not here because they're concerned about their own health and welfare

1 and not face the people in this room. I've very frustrated. Katie Beckett is awesome, and it's a  
2 service that the taxpayers pay for. I'm a taxpayer. And in principle, me even paying the \$15 a month  
3 is wrong in principle because I paid my taxes. I'm not opposed to paying \$15 a month. 4½%, well  
4 there again, okay in my house today we've got a bathroom renovation so I can give my son a bath  
5 because he's getting big. That's an expense that no one was charged except me. I've got a van sitting  
6 out there. Well geez, I look cool in a van. Not really. So those are things that we have to incur that  
7 aren't paid for by anyone but us. And it's not a '92 but it's still stinking expensive. And so I  
8 appreciate your time and my frustration is quite high. I appreciate you listening.

9 *HEIDI McDOWELL:* Anne Newton?

10 *ANNE NEWTON:* Hello. I'm going to try to be politically correct but I'm usually not. My  
11 name is Anne Newton. I am the parent of a disabled boy who is fourteen (14) years old. I'm going to  
12 try not to cry. I am also a working single mother. I'm told I'm fortunate because my ex-husband  
13 does help out 50% of the time, but I don't think I should consider it a great thing that I don't have a  
14 dead-beat ex-husband. But anyway, I told you I wasn't politically correct. Okay, I'm also the current  
15 Board President of Comprehensive Advocacy, which is the protection and advocacy agency for  
16 Idahoans with disabilities. So, I like to think I know a little something about this stuff. One of the  
17 points that I would like to make that rather than be redundant has been pointed out yet is that in come  
18 cases some of these services provided by Medicaid, agencies are absolutely inaccessible to those of us  
19 without Medicaid. I would not have a place for my son to go after school without services through  
20 Medicaid because there are no childcare facilities for kids with disabilities. And the fact that they are  
21 asking us to take financial responsibility for our kids is amazingly ironic because that's exactly what

1 we do every day. You know, we talk about the vans and everything else, and it's nice that you're able  
2 to build a bathroom that your son can access and use, and someday I will probably have to do that  
3 because he is fourteen (14) years old and about 80 lbs., and I've got the back and neck chronic pain to  
4 show for it. I love him. He's got huge brown eyes, freckles, and he's adorable. He has never been  
5 diagnosed. They say he's one in a million. He has Autistic behaviors but is extremely social and  
6 touches hearts and lives wherever he goes. I would never ever think about institutionalizing my child,  
7 but I could see where some people might be tempted sometimes. Sorry Garrett, I didn't mean that  
8 about you. I'm curious what will happen to the 70% of Federal funds that are contributed as a result  
9 of the State funds that are contributed if in fact they are not contributing those funds because they're  
10 getting income from us or tax, as some people say and I like that. I think that's more true. So I think  
11 that's an implication that needs to be considered because the matching dollars obviously must be at  
12 risk there somehow. Private insurance premiums should be taken into account because you're asking  
13 us to double insurance. Private insurance pays a lot of those expenses, and people aren't going to  
14 carry both. You're also asking me to give a certain percentage of my gross income, probably 4½% in  
15 my case. I work hard. I'm fortunate. I've went to college. I studied hard, and I've worked very hard  
16 to get where I am, and I don't think I should be penalized for taking responsibility for my child. And  
17 my son will never be independent. Katie Beckett was made for children just like my son. I don't  
18 agree with the co-pay because the people who are most low functioning like my son are the ones that  
19 are going to be penalized most. So you are actually penalizing more with a co-pay the people it was  
20 most intended for. So please consider that when you look at solutions. And the money that you're  
21 taking from me is money that I would put into a trust fund to take care of him after I'm gone, because

1 that is the scariest thing for me, to have a son like Garrett. Sorry. I guess that's it. Thanks.

2 *HEIDI McDOWELL:* Laura Larsen? And just a reminder that we really are running short on  
3 time. We have several speakers left. Several people still want to give their testimony. (*Inaudible*).

4 *LAURA LARSEN:* My name is Laura Larsen. I have a thirteen (13) year old daughter with  
5 Autism. And just like everybody else, you find out your kid has special needs and you don't know  
6 what to do, and your life is just torn up. And then me and my spouse got divorced, and then had a  
7 special needs child. I mean how many special needs people are divorced? And I sit here and look at  
8 everybody that's together. It's great. But you get the letter and you got to pay, we're paying 4 ½% of  
9 our income. You know, just like I'm sure everybody, you don't get to take vacations. You don't get  
10 to go to Hawaii. You have other kids that don't get to go to Disneyland. And if you're lucky to have  
11 an extended family that understands your child that you can leave them with, but if you don't, and  
12 you know the respite care, you have to find somebody that can watch your child, it gets to be very  
13 difficult. And now you're going to incur a \$600 a month payment. And I just don't understand how  
14 that is fair if you were to go up to someone and say give me 4½% of your gross income to insure your  
15 child. Our daughter will never live independently. You know, some of you are lucky your child  
16 might, but I still consider my child a productive member of society. She teaches people more than a  
17 lot of regular kids do. So to say you're going to have to choose between a group home at this stage or  
18 insuring your child, I just don't think it's a fair burden to pay on parents who are extremely stressed  
19 out already, you know. That's all I have to say.

20 *HEIDI McDOWELL:* Tammy Gilstrap?

21 *TAMMY GILSTRAP:* Well I don't want to be redundant, so I'll pass.

1           *HEIDI McDOWELL:* Diane Miller? Diane Miller? Robert Miller? Laurie Borrowman?

2           *LAURIE BORROWMAN:* My name is Laurie Borrowman. B-O-R-R-O-W-M-A-N. I'm the  
3 mother of a fourteen (14) year old son with Autism who is nonverbal, who will never live  
4 independently. To ask families to take financial responsibility, you're asking the families who are  
5 already taking financial responsibility for their children. According the Federal poverty guidelines,  
6 my family which is a family of four, is considered low income in the amount of money that we make.  
7 We are \$200 above the cutoff for the \$15 a month payment and we have to pay almost \$120 a month.  
8 We already pay \$450 a month for private insurance. Last year when my son broke his arm, it was a  
9 cost of \$2,500, \$30 of which Katie Beckett picked up. My son gets some durable medical equipment  
10 that since they made the cuts in Medicaid, every month I'm told by the provider I have to find another  
11 provider because Medicaid is not paying enough. So the last four months I've had four different  
12 providers for that service for my son. I also want to point out that families that have children with  
13 disabilities, especially Autism, have a lot of expenses that are not taken into consideration. We have  
14 a deck around at the front of our house that we have a fence around so that my son can go outside and  
15 he has a chance, he rushes the door, my son will go out and sit next to a busy street because there's  
16 rocks next to it and play with the rocks while these cars are going down the street 40 mph if he gets  
17 out. So we have to keep an eye on him 24/7. And we just had to install \$1,500 worth of fencing  
18 around our decking because he broke through the vinyl fencing that we've had since he was about  
19 three (3) years old, and now that he's fourteen (14), he's realized he can break that. So we had to go  
20 to the expense of putting in rod-iron fencing that we've been working on ourselves because we can't  
21 afford to have anybody else do it, for four days, getting that in so that he won't rush past us as we're



1 going out the door. We also had to install the double-keyed locks on all of our doors. We have to  
2 keep everything locked up. There are a lot of expenses that we are already taking responsibility for,  
3 and it's not even including, my son has problems because he has Autism he's walked on his toes so  
4 his feet are turning in. He's not someone who they can do surgery on so we have to buy him new  
5 shoes every four or five months because he wears his shoes down. And when you are already low  
6 income, these expenses add up quickly. And like I said we already pay \$450 a month for health  
7 insurance. If I don't feel like a service is doing anything for my son I try to be responsible and I don't  
8 have my son get that service. I only do it if it's something that I can see is helping him. I'm very  
9 frustrated by this. I'm frustrated, the way that people with disabilities are discriminated against in this  
10 country, and I think that we as families of children and people, and friends of people with disabilities,  
11 need to stand up and start doing some of the things that other minority groups have done in this  
12 country to make sure that this does not continue. Thank you.

13 *HEIDI McDOWELL:* Debra Koetter?

14 *DEBRA KOETTER:* Hi. I'm Debra Koetter. I'm new in the system. 2007, she lost  
15 movement of the left side of her body. 2008 or so Katie Beckett was such a blessing to us financially.  
16 She, potentially she could be, if her disease continues, which it hasn't because we were able to get to  
17 the Mayo Clinic and paid all the bills on our own before we were able to find out that we didn't  
18 qualify for Medicaid, but Katie Beckett would help us because we were willing to be working class  
19 citizens. So we did find some help even though we have our degrees and we are willing to work.  
20 The economy has been going down for quite a while. I was forced out of being a stay-at-home  
21 mother so that I could help provide for our family. She became disabled in '07. I have to get a

1 different certificate in order to keep working because I'm on alternative certification because there are  
2 not jobs for specialized, enough jobs for deaf educators, and that's what I am. I'm teaching Special  
3 Ed. now, but Katie Beckett has been a blessing to a lot of hard working families who are willing to  
4 work instead of let their incomes fall below the cutoff. And my husband and I are completely against  
5 the 4% flat rate. We are willing to pay, but we need to rethink it and it needs to be from people who  
6 know what they're dealing with. That's all. Thank you.

7 *HEIDI McDOWELL:* Steve Young? Jim Bayley?

8 *JILL BAYLEY:* Jill.

9 *HEIDI McDOWELL:* Jill. Sorry Jill.

10 *JILL BAYLEY:* Good evening. I wanted to point out, as many of you in this room, that we as  
11 a two income family pay a premium already to have health insurance. We have medical insurance  
12 that pays 80% of the cost of our medical bills up to a certain point. Then they pay 100% of our bills  
13 that are medical pharmacy-related. We as a dual income family are in a higher tax bracket, in turn  
14 paying more into the Medicaid program already. We as a dual income family will be charged 4.5% to  
15 pay a premium that we already pay through our taxes, which many of you people already mentioned,  
16 but I think needs to continue to be mentioned, because I am not willing to pay. I am not willing to  
17 pay a penny, because I already pay. I already pay for the Medicaid system because I go to work and I  
18 pay my taxes. So I'm not willing to pay. Forcing us to drop our health insurance is what this is going  
19 to do. We will drop our health insurance and we will take that 80% that we pay already. A week-  
20 long hospital stay was \$10,000. \$8,000 of that you can pay. So making us pay, excuse me, another  
21 \$600 a month, which happens to be our van payment so we can take our child to his services without

1 continually ruining my back, will force us to drop that health insurance and expose our child to a  
2 lesser standard of care that we as educated individuals and dual income families want for our  
3 children. We are taxed in the Medicaid system the least. To slap a 4.5% premium on us is a penalty  
4 contributing to society, contributing to the work environment, and most of all, contributing to the cost  
5 of our son's healthcare needs. You say in your letter, "We trust you understand the need to have  
6 families help share in the cost of Medicaid coverage for their children." We already do through our  
7 taxes. I do not believe this is the solution. It's like many of you have mentioned, it's a discrimination  
8 against us families that have income. And we try so very desperately to have a standard of living  
9 where we can afford to have a bathroom remodel so my son can have a bath, something that he  
10 enjoys. He has Cerebral Palsy. He's non-mobile, nonverbal. The best part of his day is to relax in  
11 the bathtub. And to get him in and out at 60 lbs. is killing us. And I'm not going to be able to keep a  
12 nurse in the house. No one will want to if they are going to have to lug that kid in and out of the  
13 bathtub, because it's the one thing that will help his muscles relax during the day. That's the one  
14 thing he really, really enjoys. And I'm paying for that myself, as well as the van. I went back to work  
15 full-time in October so we could afford the van. And now with this additional \$600, I don't know  
16 what we're going to do. We can't pay it, and I won't pay it. I hope they rescind the rule.

17 *HEIDI McDOWELL:* Adam?

18 *ADAM DUARTE:* Here. My name is Adam Duarte. D-U-A-R-T-E. That is my beautiful  
19 little girl up there making all of the noise earlier. My story is a little bit different than yours. She's  
20 not Autistic. She was born normal. She was a shaken baby eight years ago next month. She cannot  
21 see, partially paralyzed on her left side, she has a massive brain injury. But we have kept her at home

1 for the last eight years. She is a very expensive child. I'm not going to disagree with the costs on  
2 that. But when it happened I had very good insurance from my employer who covered all of the costs  
3 of the initial surgery, brain surgeries, the months in ICU, the Elks, the whole nine yards, and then  
4 after that the real expenses also come every day. And two years ago I had to sell my house because I  
5 could not deal with the bathroom issue. Just like all these people here because she's getting big. And  
6 if you saw my wife, she's about almost as big as my daughter. And so we did that, and I did the  
7 math, and actually checked my math, and it was cheaper to build a new house than to do a renovation.  
8 And so I did. And I actually wrote off \$20,000 on a new house as a medical expense, before the  
9 bathroom, the widened doors, the ramps, everything. But when I bought the new house, I doubled my  
10 house payment. So in doing that, I'm barely making it. There's no money left over. You know, and  
11 then if you take my wife the last eight years, she's had to stay home. My daughter is full-time care.  
12 She cannot feed herself on her own. She can't toilet herself by herself. She can walk with help if  
13 you've seen her get up. I mean, she is very limited. She can only verbalize a few words. And so she  
14 needs total care. So my wife has been home for the last eight years. If you take somebody, she's just  
15 had her high school education, but make \$12.25 an hour, because we were two incomes and went to  
16 one, that \$200,000 that the State didn't pay because we did the job. She stayed home. That's just in  
17 her time. Now for me, I've only got a high school education. I didn't have the luxury of going to get  
18 a nice \$80,000 job. I worked 50, 60, 70 hours a week to make the money to support my family. And  
19 the other thing people are missing here is this is the old welfare trap. They set a sliding scale. The  
20 more you make, the more they take. So, if I go to work overtime to get my eleven (11) year old some  
21 football shoes for football, there's the extra \$50. Well, they take the \$50. Screw football. No

1 vacation in eight years. Nobody can take care of my daughter full-time. I mean, she gets evaluated.  
2 They do suggest, I mean this was a few years ago they suggested that she be in an institution. My  
3 wife came home and cried. I promised that wouldn't happen. So, another that has been mentioned  
4 here is we don't know who's on the end of this tape recorder, but I did call, I looked on the internet  
5 and called everybody that sat on the Health and Welfare Committee for the State. And I called every  
6 single one and left a message. Do you know what? One representative called me back. One. So you  
7 guys need to flood those phones starting tomorrow. Call their home. Call every number they've got.  
8 Call them. Call Butch in his ivory white tower up there, because he was born with a silver spoon,  
9 still has a silver spoon, doesn't know what it's like to work like we do and have to take care of their  
10 children. He's over there, "Yeah, we need roads." So that's true. So guess what, if I can't afford the  
11 van to get my kid to services, the road doesn't do me much damn good, does it. Okay. I mean, we've  
12 got to call these people and get on it. And call the Director of Health and Welfare. Don't settle for  
13 anybody less. Jam those phones tomorrow. Jam them. I mean, we have to stand up for these  
14 children. Once again, it's who does the government pick on? The rolling elite? No, they pick on the  
15 people that are indefensible, that can't stand up for themselves. You are your children's arms, legs,  
16 brains, and muscles and mouths. Do not let them stomp on us. Stand up and fight. I offered that  
17 legislator that called me back, I said I will testify down there in front of the full forum anytime. If  
18 they need somebody to speak to it, I will speak to it. And we all need to get up and do it. So, this  
19 whole welfare system, it's a welfare trap, and Medicaid needs to look in its own house before trying  
20 to spread apart to the rest of us. In case you all don't know, a lot of people are losing their jobs right  
21 now due to Medicaid because they made a ruling last year that became law and it's taking effect this

1 year for service coordinators. Do you all have service coordinators?

2 *SEVERAL PEOPLE:* Not anymore.

3 *ADAM DUARTE:* Exactly. Not anymore. Because, our lady who was a service coordinator,  
4 she was a service coordinator for the last sixteen years, now has all the contacts in the world and  
5 knows everybody. Right? Well guess what, they made a new rule you have to have a college degree  
6 to be a service coordinator. So now I get this, well I must be getting old because she looked like she's  
7 sixteen, she's probably twenty-one, she comes in there smacking her gum, you know, "I'm your new  
8 service coordinator." And I go, "Geez, what do you know?" You know, so now you just took  
9 somebody that you're paying, that knows what their job is, been doing it for sixteen years, and now  
10 you're paying somebody more that doesn't know their job. Medicaid's got to get its own house in  
11 order before they come looking on my back again. And that's all I've got to say.

12 *HEIDI McDOWELL:* Ron Gambassi?

13 *RON GAMBASSI:* Yes. I came in a few minutes late. I wonder, am I the last one on the list  
14 or do we have others to go yet?

15 *HEIDI McDOWELL:* Got about ten to go.

16 *RON GAMBASSI:* Ten more to go.

17 *HEIDI McDOWELL:* Yes.

18 *RON GAMBASSI:* So my name's Ron Gambassi. Spelling is on the sign in sheet. I'll make a  
19 few comments about some of the same themes that we've already heard here, maybe with my own  
20 perspective. First of all, to the gals who mentioned putting money away for a trust fund, I happen to  
21 be a licensed investment advisor and I can tell you that that trust fund is going to have to be about

1 \$500,000 by the time you and your spouse, if you have a spouse, are gone to take care of your  
2 children for the rest of their life. Apparently, we were reading the mail the same night that Angela  
3 was, and we know Angela because we tend to run in the same circles in this disability community.  
4 And my wife read the letter and she said, "Oh, this is not good." And of course that's not good when  
5 I hear her say this is not good. And she explained what it was about and I looked at it and I said,  
6 "Well, I guess we don't need to read the second letter," because in our case, like Roger here, we have  
7 multiples with disabilities who are in the Katie Beckett Program. And I know at least two families  
8 who have triplets as kids who are receiving services. We, like many of you, have primary insurance.  
9 We pay several thousand dollars a year for the premiums so we have insurance, and now this is  
10 several thousand more for the (*inaudible*), right. The State of North Dakota has a shared program as  
11 well, but they said folks that are paying primary insurance get a drastically, drastically reduced  
12 premium compared to those that don't have any other insurance. You know, Idaho is already one of  
13 the most progressive tax structured states for income tax in the nation. I think top 5. That means  
14 7.8% income tax, one of the highest in the nation. And you hit the maximum rate of the State income  
15 tax at guess what, \$23,000 for a single family earner, only \$43,000 for a married couple to pay the  
16 maximum income tax in the State of Idaho. So you know, like a couple of other folks mentioned, you  
17 know when you add 3%, 4½% on top of that, it starts to feel a whole lot more like a progressive tax  
18 structure than a share arrangement. And you know, there are a lot of things we spend millions of  
19 dollars in the State on. The State park system costs millions of dollars, the roadways cost millions of  
20 dollars. You know, my buddies who take their boats to the State parks every weekend and get to use  
21 those, God bless them, it's a wonderful thing. They shouldn't, and they don't pay every time they

1 walk in, you know, these kinds of high rates because they have the ability and luxury to be able to  
2 take advantage of that. We don't have the ability to do that. Our girls get four tube feeds a day, an  
3 hour each time. So I don't begrudge anybody for taking advantage of the things in this State, but this  
4 is just one other example of the same kinds of things in the State that several people have already  
5 talked about should be covered from the bucket of money that goes into the State income tax coffers.

6 You know, a lot of us have stay-at-home, one of our spouses in the family stay at home, right?  
7 Sometimes that's out of choice. Sometimes, in most of our cases, it's probably out of necessity to  
8 take care of one, or two, or three of our disabled children. So, you know the uniqueness of the Katie  
9 Beckett Program was built on the foundation of it wasn't financially based, it was need based, and  
10 you know, this is throwing that whole premise upside-down. There's another aspect we can avail  
11 ourselves of. We don't in our family, maybe you don't either, but we can get reimbursed for mileage  
12 taking these kids all around Meridian, and Boise, and everywhere else. We don't bother to do that. I  
13 couldn't in clear conscience do that, because the things we get that are the real big ticket items like  
14 therapy programs are what we really wanted the benefit for. So we wouldn't dare ask the State to pay  
15 us to reimburse us for mileage for gas and so forth. So, you know I would just say that I think this is  
16 an opportunity to really do this right. Build a public and private partnership. Figure out the numbers  
17 of people affected. Figure out how much money the State needs to be made whole because this is a  
18 real issue, it's a real cost. We've put ourselves, you know, as part of a team to work this out together,  
19 and I think that's the way to sort this out. And I thank you for your time.

20 *HEIDI McDOWELL:* Jennifer Petersen?

21 *JENNIFER PETERSEN:* Hi there. My name is Jennifer Petersen, and I am the parent of the



1     cutest fifteen (15) year old little girl you've ever seen. And her name is Paige, and she is Autistic.  
2     And like you, my daughter was born perfectly healthy. To be politically correct, I feel like I am a  
3     victim of vaccines with my daughter's autism. I've argued with every nurse that wanted to have a  
4     fight with me. And so subsequently I ruffled a few feathers and I don't mean to offend anybody, but I  
5     believe that I'm very much entitled to my own opinion. When my little girl was born, she was  
6     progressing three and four times ahead of what she should have been doing developmentally. She  
7     had at eighteen months a 24 to 30 word vocabulary and was starting to speak in sentences until she  
8     had her shots. So autism to me when we received that diagnosis was devastating. I had a doctor look  
9     me square in the face and tell me that my daughter would never say "mama" ever again, and I picked  
10    my little girl up and I told her that was not happening to me and to my family, and we left. And then I  
11    was able to be blessed with an early intervention program that has completely changed our world.  
12    And I never in a million years ever thought that I would ever hear my little girl call me "mommy".  
13    And because of the therapy that she has received since she was 3½, 4 years old, and all of that being  
14    made through Katie Beckett, I know that not having these therapies are not an option for a lot of our  
15    children. It's not an option. This was confirmed for me in October. They just had DT therapy until  
16    she qualified for IBI, and she just recently finished her three years of IBI, and devastatingly to me, she  
17    no longer is eligible for IBI but she needs it desperately. She needs it desperately. In October, the  
18    23<sup>rd</sup>, I woke her up to get her ready for school. She goes to Sawtooth Middle School in Meridian.  
19    And I woke her up and she hugged me, and I asked her if she had a good sleep. And her very limited  
20    vocabulary is "mommy", and "daddy", and "yes mom", and "Sonic", and "McDonalds", and "french  
21    fries", and "Diet Coke". And that morning she told me that she had a great sleep, and I told her it was

1 time to go get in the bath, and my daughter went to go get into the bathtub, I'm sorry, and she had a  
2 grand mal seizure in the bathtub. It scared me to death. And my husband (*inaudible*) and we got her  
3 out of the tub and got her to the hospital, and they had no indication of what brought it on. And I was  
4 so afraid that my daughter was dying right in my arms. Because of all of that, when she came to, I  
5 wouldn't let her out of my sight for days, weeks, and almost three months. And because of that, I  
6 refuse to let her go to school, and I refuse to let her go to her therapies, and I refuse to let her finish  
7 her case of IBI that she needed because I couldn't stand the thought of her not being her with me if  
8 she should have another seizure, which she did in November. But as I look back now and know that  
9 she did not have those abilities to have those therapies then until April we started again with the DT,  
10 the regression that she took was unbelievable. Her behavior skyrocketed and she became aggressive,  
11 and she was mean, and crass, and (*inaudible*), and it became a problem for everybody in our family  
12 and anyone who came into our home. As we have started moving forward with the therapy, she is  
13 now gone six, seven months without a seizure, eight months without a seizure, and I'm starting to feel  
14 like I can breathe again, until I stand here and talk to you. I'm so sorry. But she is now receiving her  
15 DT therapy again. I wish it was IBI. They're telling me that they will help provide IBI for her at her  
16 new school. She is getting ready to transition to the new Rocky Mountain High School. Again,  
17 another traumatic experience possibly for her that could push her over the edge yet again. I have seen  
18 what not giving therapy to my daughter has done to her. And that's not an option for me anymore.  
19 And it shouldn't be an option for any of you. We shouldn't have to make that choice. They cannot  
20 keep us from doing everything that we need to do to be advocates for our children. It's all been said,  
21 and I know that we pay taxes. I pay a lot of taxes. I went to register my car and it cost me \$40 more

1 because of those stupid HDR things. Anyways, sorry. You don't play with children's lives. So I  
2 agree with, is your name Eduardo?

3 *ADAM DUARTE:* Adam.

4 *JENNIFER PETERSEN:* Adam. Call them. Let them hear from us. I think they're chicken  
5 for not being here tonight. Mr. Tape Recorderman. Mr. Tape Recorderman, whoever you are, these  
6 children have names. They are people. They are not a collective group that you can terrorize and  
7 take away their rights to have a normal life just because you think that we haven't paid enough.  
8 That's all I had to say.

9 *BONNIE STILES:* I'm Bonnie Stiles. We have six children and our second to the youngest is  
10 Adam, and he has Downs Syndrome. He's eight and one-half (8½) years old. And I agree with  
11 everything that's been said here tonight. One thing that has not been brought up yet though, in order  
12 for Adam to qualify for Katie Beckett, he has to take an IQ test. He had one when he was about five  
13 (5), and he just barely had one for his nine (9) year, since he's going to be turning nine (9) soon. That  
14 test cost the State money. It took my time. It took the counseling center's time. They were a  
15 complete waste of time and money. It told the State nothing. He was not able to take the test and  
16 answer the questions and do the activities that were required of him. His diagnosis should be enough  
17 for him to qualify for Katie Beckett. Medicaid, Medicare, Medicaid and Health and Welfare should  
18 clean house and figure out what do they really need. What can they clean out before they start taxing  
19 us? What can they get rid of? These costs that they incur with the counseling centers, get rid of it.  
20 Let Katie Beckett be based on a diagnosis, not on some IQ score. That's just one thing that they can  
21 do to reduce their cost and not require us to pay. Thank you.

1           *HEIDI McDOWELL:* Janet Loomis?

2           *JANET LOOMIS:* I drove over from Mountain Home because this was the closest place. I'm  
3 Janet Loomis. I'm 100% disabled veteran with a daughter who's handicapped with Downs  
4 Syndrome and a hearing impairment. The last time this was tried, the cost of collecting was more  
5 than what was collected. Right now, we don't qualify for CHIP B because I'm in receipt of Champ  
6 VA, which is provided by the Federal government. This insurance pays 75% of the allowable  
7 charges. This covers a portion of Barbara's expenses. While we still have to pay for the co-pay for  
8 our other children. If we did not have the Champ VA for insurance, we would qualify for Medicaid  
9 and we would not be paying all the expenses for our other kids. When on the medical expenses we  
10 are already bearing extra expenses for our handicapped child. We pay for her hearing aid batteries.  
11 We have to buy extra clothing because she has accidents several times a day. We have to buy  
12 replacement clothing as she stretches her legs up inside the clothing and just stretches out, wrecks the  
13 clothing. We have to buy waterproof mattress covers. We have to do extra laundry. We have to buy  
14 deodorant for the laundry. That's \$40 a gallon. It takes one cup for each load, two loads per week.  
15 She has to have special food. She can't eat all we eat, what we eat, because she has a texture  
16 sensitivity, so we have to provide extra food for her. She has yogurt for her digestion, liquid  
17 vitamins. She's very, we're trying for her independence, so she pours her own milk, about half of it  
18 goes on the floor, some in the cup. We have to keep a separate refrigerator to store her yogurt  
19 because she'll eat all the yogurt in the refrigerator. We have to store it separately so she doesn't eat  
20 everything. She eats bread. She'll get that out herself, leave the loaf out. It wastes bread but she eats  
21 that every day, has the whole wheat for the fiber. We have to get her flavored water so she'll drink

1 the water to help her digestion. She won't drink, it's very hard to get her to drink just regular water.  
2 She requires a listening program so that she can focus so she can learn during her therapy sessions.  
3 We, originally did start, we used the family support fund for a while when we were, before I had  
4 gotten the 100% disability. (*END TAPE 2, SIDE A*)...So other families who are not doing as well as  
5 we are would have the family support funds, we have been paying for her listening program. That's  
6 \$55 a disk. It's \$20 for the CD player which lasts about three months and then we have to buy  
7 another one. \$150 for the special wide-range frequency headphones. We have to pay for the  
8 batteries. She needs what they call a bear hug, which is a specialty thing for sensory input. It costs  
9 \$70. She's damaged our chairs, our couches, and our carpet beyond repair. We have to replace them.  
10 She rocks and because of her incontinence. We have purchased pads to try and protect the  
11 upholstery. We pay for respite care on a weekly basis of \$25 a week. She takes liquid pain and cold  
12 medications, and suppositories. She wears out and damages her DVDs. You know how much those  
13 costs, between \$5 and \$20 each. We have purchased sign language materials and other materials for  
14 instruction. We are taking financial responsibility for my daughter. This extra cost is not bearable.

15 *HEIDI McDOWELL:* Joy Cameron?

16 *JOY CAMERON:* Hi. My name is Joy Cameron. I did send out a letter so I am just going to  
17 bullet some points here from listening. I just wanted to point out that and ICFMR, which would be  
18 like a group home, costs the State \$176 per day. And that's the base rate, that's not including any  
19 additional therapies. The cost to our community aside from money is the emotional cost that it's  
20 going to cause. Just in the last year at our agency, I know of six families that went through divorce.  
21 The divorce rate is excruciating. The therapy needed for the families and for siblings, it's very, very

1 trying on a family. I know speaking from that personally too because I do have a son with  
2 disabilities. I don't know about you, but I'm getting tired of going to hearings. This is the fourth one  
3 in less than a year for Medicaid cut services. And it's been not quite a year and this isn't exactly how  
4 I wanted to spend my 21<sup>st</sup> wedding anniversary either. You know, thank you. It happens every year  
5 just before school is out when everyone's on vacation, we get to spend our whole summer fighting,  
6 but yet there's nobody to listen because it's conveniently planned that way. And I know just from my  
7 own letter going out to the legislators, probably a quarter of them have already been returned because  
8 they're not on duty, they're not taking their letters, going to automated. Who is there listening to  
9 what we have to say right now? We had it last year with trying to cut services, working with the  
10 schools. And then we had it with cutting the hours, cutting service coordination, and now this. I'm  
11 scared to go to my mailbox. And it's just down right tiring. And I know each person here that has a  
12 child with needs, it's a full-time job. And aside from the expense, you know, it takes a toll on our  
13 families. Would I have it any other way? No, never. And I dare any person that would say that it's  
14 not society's burden. It's not a burden at all. Probably one of the best things that happen in my day  
15 will be a phone call from a family saying, "I got the letter. I got approved. I got Katie Beckett. Now  
16 what?" You know, that is just like music to my ears. I absolutely love that because all of a sudden  
17 now I can say, "Okay, let's get going," you know, now the doors are open. I just got a call this  
18 morning from a family, "Well, we got our Katie Beckett." Well, obviously since they just got it they  
19 didn't get one of these wonderful letters that we got. And I was dumbfounded on what to say. You  
20 know, I wanted to say, "Great," but then I had to stop and think, "Well what does that mean for this  
21 new family? You know, dad just lost his job. Are they going to be able to pay the shared cost?" You

1 know, this last year I was told from Health and Welfare that families who don't utilize Katie Beckett  
2 services will be dropped from the program. So you are actually forced to get services to stay on the  
3 program. You have to show a need to stay on the program. So a family who takes a six month break,  
4 or a family who isn't going after utilizing every single service will actually be dropped from the  
5 program. So you're penalized for not taking advantage of the system. There's lots of new testing out.  
6 Some kids need several types of tests to find out exactly what's going on with their child. And event  
7 then when we do find out, then we get surprises like I did when my son was nine (9) and had a grand  
8 mal seizure, and now has a seizure disorder. Then now you have a whole new set of tests. Now at  
9 fourteen (14) we're looking at possibly some mental illness. So it never ends and it's always  
10 something new. Inpatient hospitalization, I'm sure there are some families here who have had to put  
11 their kids into St. Al's or Intermountain. A week there is \$10,000. One week. We are a community  
12 and we need to take care of each other. Several of the IEPs that I go to, it's actually stated that if a  
13 family doesn't sign for Medicaid, that they will not get the services that their child needs, or they're  
14 actually told, "If you get on Katie Beckett, we can provide an aide for your child." I can't even  
15 imagine how this is going to impact the schools. I don't necessarily agree with Medicaid in the use of  
16 school, but I won't even go there, but we do need to provide for the kids. You know, I'm a special  
17 educator. I'm looking at how things have gone backwards. And now we're putting kids out in  
18 trailers and we're closing down programs at schools, and we're segregating our children, and that's  
19 not okay. I know that we've all been blessed by our kids and someone has said that our kids touch  
20 lives like no one else can. I think I have the best job in the whole world and a lot of it's because of  
21 your kids. It's because of my kid even though he drives me crazy sometimes. But that care is

1 needed. We need to continue this. I like to think of myself as like a Katie Beckett ambassador. I  
2 love the Katie Beckett Program. The State doesn't pay us to do Katie Beckett. Anyone here who  
3 helps families for Katie Beckett, we don't get paid to do that, but I love it because I know the parents.  
4 It wasn't until we moved to Idaho, nine years of no services, and someone told me about Katie  
5 Beckett. So at nine years without anything, and it's been the most wonderful program possible for  
6 my son. So my goal is to make sure that every family out there that has a child that qualifies is able to  
7 get the services for Katie Beckett. Well, I hope somebody listens. I'd like to know, like someone  
8 else said, I'd like to know who is on the other end listening, and I'd like verification too of who  
9 actually does listen to these statements today because I continually feel that we come to these  
10 hearings and that our words go on deaf ears and we never get to find out what happens. Everyone  
11 here has something wonderful to add and something wonderful to say that needs to be heard. And I  
12 guess that's all I have to say.

13 *HEIDI McDOWELL:* Debra Johnson?

14 *DEBRA JOHNSON:* Hi. I'm Debra Johnson. J-O-H-N-S-O-N. I didn't get one of your cute  
15 little letters that you guys got. I got to read it in the newspaper. And the Katie Beckett Program has  
16 been a critical thing for our family and I wanted to come and share some thoughts with you tonight.  
17 My daughter, Lindsay, is twenty-eight (28) years old. When she was born, we found out that she had  
18 significant disabilities. She was born with Credshaw Syndrome which is a very significant cognitive  
19 impairment. She's nonverbal, very aggressive. She's one of the fun ones. But my husband and I,  
20 neither one wanted to get into the Medicaid system. We were upstanding people. We were Idahoans.  
21 We can take care of our own kid. And at that point in the game you got to do co-pays to the Adult



1 Child Development Center, and we actually paid for two half-hour sessions every week. That's all  
2 we could afford. And we could see our little girl going downhill so fast that when we moved to Boise  
3 when she was five (5) years old, she was at a point where she would attack people that would open  
4 the front door. We were totally lost. We were totally, totally scared to death we were going to end up  
5 looking at an institutional setting, and that's exactly what we ended up doing. We had signed up all  
6 the paperwork. And when we finally signed up to place her out of our home at an ICFMR, we had to  
7 sign up for Medicaid. And at that point, we realized we actually qualified for a Katie Beckett waiver,  
8 which we went ahead and by the time we waited for the services that she was going to get at the  
9 ICFMR, we had to be on a waiting list, and so it took us four or five months to do that. In the  
10 meantime, there was a new program called Ready-Set-Go getting ready to start up, and she was like  
11 the second person that ever got to go through the program. And based on those services, we never  
12 had to place her out of our home. She has lived twenty-eight years with us and we are the happiest  
13 family based on the Katie Beckett waiver. So I've got to say it is a critical thing for me to share the  
14 money that has been saved just on my daughter alone. She was headed towards an ICFMR. We had  
15 the paperwork, we had to go look at the ICFMR placement issues, everything was there. So this is a  
16 critical thing for me to help you keep your kids at home. The other piece, you guys have all been  
17 eloquent in all of the things you said. For ten years, I was the Director of Idaho Parents Unlimited,  
18 and fourteen years ago the State tried the exact same situation, tried to bring through this whole new  
19 plan, and it all comes down to we as families need to take responsibility. There's a misconception  
20 that we are not responsible people. And the things that you guys have said here today is critical. But  
21 there are two pieces I wanted to make sure you're clear on. These are temporary rules. Temporary

1 rules are a Health and Welfare issue. They only get ratified or adopted to go in front of the  
2 legislature. So this is one avenue you have to talk, and I understand it does feel like there is a never  
3 ending person at the other end of this. What you really need to do is get to know your legislators.  
4 And I agree with you when you say call them on the phone, but can I put a caveat on that? These are  
5 people who are just like you and me. They volunteer their time to go sit in the legislature, and god  
6 knows some of them get stuck on the Health and Welfare Committee. It's not one of the favorite  
7 things I can tell you from talking to the legislators. But they have no idea what you pay. You pay  
8 things. I mean, I have three children. My two sons can give you hours of things that they have paid.  
9 Maybe not money stuff, but emotional things. Legislators need to hear that. They need to understand  
10 that you're not just sucking down the money as fast as you can because that's a misconception. They  
11 need to understand the transportation issues, the modifications in your home, the fencing, the food, all  
12 the things that you do. And in a very appreciative way, we need to make sure we're clarifying that to  
13 the legislators, because if anybody can stop it it's the legislators. So what you need to do tomorrow.  
14 Go online. Do not send your letters to the Statehouse. Go online and you can list how to contact the  
15 legislators. Go to the Idaho State Legislative connection and it will tell you the names of the person  
16 and their home address. Pick up the phone. Particularly, start with your people that your legislators.  
17 I called mine before I came to day. Two of them called me back, one of them is out of town. They  
18 will call you back. You need to build a relationship with them. Let them get to know your son or  
19 daughter. Have them over for coffee. I've got to tell you, that is one of the very best ways to get to  
20 know your kids. And you don't have to go through all the written garbage. You know them, they  
21 know you. So that when you come into those meetings, they know you and they know the person is

1 behind what you are trying to say. So, I guess my best thing to say to you as families is you just got to  
2 hang in there and you've got to get to now these people because they have the keys to your lives, and  
3 it's critical.

4 *HEIDI McDOWELL:* Eric Stave?

5 *ERIC STAVE:* I'll pass.

6 *HEIDI McDOWELL:* Mario Puentes?

7 *MARIO PUENTE:* Puente.

8 *HEIDI McDOWELL:* Puente. Thank you, sorry.

9 *MARIO PUENTE:* My name is Mario Puente. First of all, I want to say one thing. The  
10 Department of Health and Welfare needs to rescind this. End of story. It just needs to stop. I'm just  
11 like you. I have an autistic son who's ten (10) years old. I go through all the same struggles, financial  
12 burden. I'm going to be hit 3% on this unfair tax just like a majority of you guys are. My biggest  
13 problem is now. I've got a sixteen (16) year old daughter who's not on the spectrum. Now when I  
14 have to look at her in the face and tell her that my sixteen (16) year old daughter has got to get a part-  
15 time job just so she can go to college and put herself in debt because I can't afford to now save for  
16 her. What does that do to her education and her future? Not just of my son (*inaudible*) he can do.  
17 These are the things that are so far, so much more widespread. I was able to go to college. I'm still  
18 paying that off, these student loans. Now we're going to sacrifice our future, not only of our disabled  
19 children, but now of our regular children, that we can no longer educate so that they can make a  
20 difference in our disabled children. This is going to have a ripple affect that is so far more  
21 widespread than we can even imagine. I mean, I have a sixteen (16) year old daughter. She has more

1 in her bank account than I do now. She's now hoping to save to buy herself a nice little car and be  
2 able to do these wonderful things that I can't afford to provide her now. I mean go on, look at your  
3 child, the one who isn't autistic, who has to see that you're spending every single dime. I mean, I  
4 barely see my kids as it is. I have a great job. Luckily, I have a wife who is able to stay home. I work  
5 hard so I can live this so-called American Dream so my wife can stay home, take care of our children.  
6 I mean, and do everything that she can possibly do, and everything that I can possibly do. Now for  
7 me, to have to go and tell my daughter that she can't live that dream. When we stop supporting our  
8 children, our nation's going to fail. And for the United and for the people of Idaho to stop treating  
9 children and disabled people, I mean what's next? Elderly who can't fend for themselves? Oh, that's  
10 you know, that's going to be the next thing. "Oh, that's just part of growing old. Don't worry about  
11 them. Why take care of their disabilities." Where is this going to stop? We're getting to the point  
12 where we need to stand up and we really need to say, and if we aren't angry right now then we're not  
13 paying attention. We need to do something and we need to do it drastically. You have every other  
14 ethnicity out there. You have every other group out there raising hell about their civil rights, about  
15 their rights. Where are our children's rights? Not just our disabled children, our regular children,  
16 because this is going to affect them. I don't know how my daughter is going to go to college. I don't  
17 know what I'm going to do if I now have to pay this extra, for me it's almost \$260 a month that I now  
18 have to come up with. Well, I don't have a 401(k) anymore. My 401(k) is my life insurance. If I  
19 have to pay this \$260 a month, guess what? I don't have life insurance, which that's what's going to  
20 take care of my children when I'm gone. That's it. I pay one bill on time or two life insurance  
21 policies on time every month without fail. That's my life insurance policies, because God forbid,

1 something happen to me, my family is screwed. And that's it. That's going to be my only daughter's  
2 education. I'm not going to see her graduate. I don't know what else we can do here. This is far  
3 worse. And yes they say it's temporary, it's always temporary. No, I'm sorry guys, we need to be  
4 real about this and we need to start paying attention, read between the lines, and we need to see what  
5 this is really affecting. I'd love to have another child, but I'm like I'm stopping at two, because I'm  
6 struggling right now. At 3% of my income, I can't do it. So, I mean, I hope they realize it's one  
7 thing, I mean it's one thing to pick on a defenseless child who we are the only advocates that they  
8 have, but it's another thing for children who haven't learned to defend themselves who are still in  
9 high school, who are still learning things, who are getting taught as long as you do what feels good to  
10 you then everything's alright. No, they're not given the same opportunities. In Wyoming, in other  
11 states, they are increasing IBI benefits. Instead of getting them for three years, you can go to four  
12 years. Plus after that, they're given \$25,000 a year allowance for after your fourth year, where Idaho  
13 is cutting benefits. These are passing every month and it's because we're lazy, guys. How do we  
14 sleep at night? Yeah, we're letting them screw us. And it's not really our disabled children, it's our  
15 children, our so-called normal children. I hope you enjoyed going to college because not only are our  
16 colleges expensive and they're getting worse every year as far as quality, but our children aren't going  
17 to go to them, aren't going to be able to. At least mine aren't. I don't know how. I'm going to have  
18 to tell my daughter, "Hey, get a student loan. I hope I kick off of something so that you can have it  
19 all." I don't know. I mean we really need to, and I'm one, make phone calls, that's great, but we get  
20 to know people, faces, contacts. It's not about what you know, it's all about who you know. We  
21 need to meet these people. We need to make contact. I've only lived here in Idaho for six years, and

1 I used to work at Boise State. I'm an electrical contractor, a project manager, and I have a great job. I  
2 worked at Boise State. I met a lot of people just by being polite, being straight forward, and knowing  
3 what I want. We need to want the same thing because I tell you one thing, I worry more at night  
4 when I'm thinking, "Gosh, if I would have just taken that one." I challenge you, if we all spend one  
5 hour a night, and I know that seems like a lot, believe me I know. I never wake up next to my wife  
6 because she's always (*inaudible*) my son to bed with my son lying next to me somehow. I don't  
7 know, it just happens. So if we can just take one hour a night and really sit down, write something,  
8 meet someone, talk to someone, and create this chain, it's going to make a huge difference. But this  
9 is unfair. This is what it is. I won't call this sharing. This is just an unfair tax. That's all it is. In  
10 every letter I write, in everything I'm going to do, that's what I'm going to call it, because I'm not  
11 going to beat around the bush and pretend it isn't what it is. We need to do this because it's affecting  
12 more than just our disabled children. That's all I have to say.

13 *HEIDI McDOWELL:* Darlene Greenhalgh?

14 *DARLENE GREENHALGH:* A couple of days ago I took my kids to Roaring Springs and  
15 Whazoo. I am a single parent. My now ex-husband of two and a half years decided he couldn't  
16 handle my children's disabilities and left. And so I was forced to go on Medicaid, and today I ended  
17 up finishing up some of the process for them to go through psychosocial rehabilitation (PSR) and  
18 some of the questions I had to answer were very tough. It's hard to answer those questions on these  
19 forms that they have us answer when you love your child so much and you have to face so many  
20 negative things about them. And that's not fair. I'm studying right now and going to BSU to be a  
21 Special Education teacher, and both my sons, one's eleven (11), he has Asperger's, nonverbal

1 learning disability, ADHD and a couple of other things going on. And my youngest who is now  
2 seven (7) is 100% Autistic, ADHD, and he might have some psychological issues going on too. I  
3 might be on Medicaid, but when I get done I'm planning on going and teaching, hopefully not into a  
4 public school because I don't know if they'd like me. But I would be utilizing Katie Beckett because  
5 I would not qualify for Medicaid services any longer. Temporary in the State of Idaho does not mean  
6 temporary. I've lived here since I've been thirteen (13). I remember them putting tax on food and  
7 said it will only be temporary. Well, you know, twenty-some odd years later, where's the temporary  
8 going to end. For those who are listening on the tape, I was limping. You couldn't see that because  
9 you're a tape, but my son's provider came with me because once a year I take my kids on a grand day  
10 out to Roaring Springs and Whazoo. Well, at one of the put-put holes at Whazoo, there was a split  
11 level and my oldest son's service provider and I were on top and the boys were on bottom and all of a  
12 sudden they started yelling at each other, and they were getting ready to hit each other in the head  
13 with the golf club. And it wasn't sword fighting, it was literally I'm going to kill you. I turned  
14 around and I fell one and a half feet on pavement, hit my head, ruined my leg, ruined a lot of parts of  
15 my body in just a second. When he had to leave, because he had other obligations at 6:00 and I was  
16 on my own again because expectations had been set for my children, my children did not understand  
17 that I was hurt even though I told them that I was in pain, because they're unable to understand that. I  
18 had to go through laser tag. I had to go through the river one more time. I just put my foot down and  
19 said, "Okay, I'm not climbing stairs." You know, in the school they say, "No bullying zone." That's  
20 a Federal law. Columbine. There's a reason for it. Yet this is what they're doing. They're bullying  
21 us. My son today wanted to be here and I wouldn't let him because he would have blown up, literally

1 (inaudible). And all he kept on saying was, "Mom, what would Katie Beckett think about this?" A  
2 woman who from birth had a tracheotomy, who was told that she should be institutionalized. My  
3 oldest son should be institutionalized. I won't do it. No matter what. And my youngest will  
4 probably end up in that direction too, but I'm not going to do it. But most of the kids and the  
5 families, what's going to happen to them as they get older or turning eighteen (18)? There's only  
6 going to be a couple of places they can go. It's going to be either institutionalization or to prison.  
7 And how is that going to help us? I agree with everything that's been said, but it's time, you know I  
8 believe in the Gandhi way of nonviolence. And that is the way, it's nonviolence. And we need to  
9 start speaking up. Did you guys know that on the websites I did research that Idaho is the fifth worse  
10 place in the United States to live for disabilities? Thank you.

11 *UNIDENTIFIED SPEAKER:* Was it something I said? First I want to say thanks to these  
12 gals and everyone that stayed late past the 7:00. I think we should all appreciate that. And just  
13 hoping that Katelyn, my daughter, doesn't realize I'm over here and not by her. So quickly, I'd like to  
14 just share a few points. I asked a question today. I actually didn't get a letter. I had a notification  
15 from my developmental therapy provider, so I did some quick checking, and there is no sunset or  
16 limit. The temporary rule is the way that the current item is written because they've enacted it with a  
17 date of July 1<sup>st</sup>, meaning that it's temporary until such time that it is ratified, if it is ratified. There is  
18 no language in the ruling right now that identifies a time, or a sunset, or a point of review. So, this is  
19 not a temporary task. This is, "We're changing the system and this is how it would go forward."  
20 Okay Katelyn, that's my first. Anyway, number two. Income. Gross Income. I have a family of  
21 five. Katelyn is a twin. She has Down Syndrome. Her brother is not, her younger brother is not.



1 Both me and my husband work from home. We are self-employed. We are educated. We are paying  
2 off the student loans too. But we made a choice to be self-employed from home so that we can each  
3 take care of our children together, and as such we earn considerably less working for ourselves than I  
4 would as an architect working for a larger firm. Made that choice, happy to have made it. However,  
5 my income that I claim on my taxes after business, and I have to do S-Corp so that I can claim what I  
6 actually bring home as opposed to what I earn through the business, is about \$36,000 before taxes. I  
7 am the primary breadwinner. My husband is the primary care provider. In architecture, you know,  
8 building is down. I had a half a year's worth of income last year that I cannot collect on because  
9 projects cannot get financed. It's not my clients' fault. This is a sign of the times. But still I go out  
10 and I find the extra work to take care of the bills that couldn't be paid from my clients in order to pay  
11 my bills. But if I take that that \$36,000 and I figure my taxes and my take-home is about \$2,300 for a  
12 family of five. Now according to the FPG, I'm not at a poverty level. Do I have any extras in my  
13 life? I do have Starbucks and the occasional six-pack of beer, but not every month. There is no  
14 buffer here for savings. There is no buffer in my budget to save for college for my other two boys. I  
15 do take time and money though to make sure that my daughter receives the extra nutritional value and  
16 things that we have identified make a difference in our family's health. We are responsible for those  
17 other items. Katelyn had open heart surgery at seven and a half (7½) months and she was discharged  
18 in three and a half days. I think I can say that she's one healthy little girl. But in this lack of buffer in  
19 my budget, even \$15 which I might qualify, depending on if I'm self-employed. How are they going  
20 to analyze my income. Is it monthly? Is it yearly? What happens when I'm successful again? Am I  
21 going to get hit with an SSI thing that happens where it's like, "Oh, well now you're making too

1 much money and you owe us \$10,000.” Where are the definitions in this rule that say how it works  
2 when something happens? Those are my questions. I’m willing to continue to do my part. I’m  
3 willing to try to come up with \$15 a month. But what happens when I don’t get the cash flow for six  
4 months and I don’t have \$15. Like two months ago I couldn’t have given you \$15. So then I go to  
5 collections. I think many of us have been to collections now recently. I know I have. And what  
6 happens to that \$15? I’ll give you a mathematical example. \$15 times four months is \$60. Now, I  
7 talked to someone today, very nice. Again she said, “We’re only going to go to collections when it’s  
8 serious.” Well, what’s serious? Is it time or is it money? Because in normal collection practices, it’s  
9 time, and four months is seriously delinquent. So now let’s take that \$60 example. \$60 after four  
10 months goes to collections, possibly. I’m just trying to give you an example. It goes to collections.  
11 Now there’s a collections fee. Who’s paying the collections fee? Standard collections would say oh  
12 it’s somewhere between \$30 to \$50 for a collection fee. We’ve gone from \$60 to possible \$110, and  
13 I didn’t have the \$15 to start with. Okay, so now we go to collections. And some collection agencies  
14 will really work with you. Some will not. Some will say you have \$30 or we’re going to court.  
15 Okay, let’s go to court because I’ve been there too. I have managed to pay the bill every time before  
16 they actually took legal action, but you go to court and now, regardless of the bill, regardless of the  
17 dollar amount, there is \$500 to \$800 in attorney’s fees. So what was \$15 became \$60, becomes \$250,  
18 \$500, and it’s on your credit history. So now I’ll use myself as an example. I’m self-employed. I  
19 have a business. I’m educated. I’m an architect. That sounds pretty upstanding. I used to employ  
20 two other people. I no longer employ those people. And if I’m going to build my business or just  
21 keep my home, or we get any kind of financing, my credit history is important. Now, I’m busting my

1 tail to clean up and make sure my bills are paid, and living on \$2,500 a month or less, and being  
2 home with my family which is a social and family decision that we have made, and I'm trying to  
3 grow my business, and participate with jobs for other people, that I now have a credit history report  
4 that is negative, that only makes it harder to do. So I question three major things about this. One,  
5 there is no sunset or limit. Why not ask for our participation for three (3) years and then revisit this?  
6 Why not make it a flat fee regardless of your income if you have to charge at all? I don't agree with it  
7 in the first place so I'm looking for compromises. And then, where is the language to say, "Here's  
8 how we collect. Here's how we mediate. Here's how we try to work with people," to keep them  
9 from going down this path, because nothing is good about collections. And then I agree with several  
10 other statements. My daughter has Down Syndrome. Her condition is not going to change. I fully  
11 expect her to live an independent life. I was a little sad to realize that a few years ago because I kind  
12 of like the thought of her being at home. However, she will be independent because she's that way  
13 already. But her condition does not change, yet I spend 40 to 80 hours a year on paperwork. We go  
14 through the IQ test. We go through all of those tests and you say, "Why? The condition doesn't  
15 change." Why not save the money from those exams which I think are unnecessary on conditions  
16 that will not change. It's a genetic chromosome. Your chromosomes aren't going to change. Let's  
17 take that money and apply it toward premiums. The original purpose of Katie Beckett. I remember  
18 being pregnant. All of a sudden, wow, I'm having twins. I thought I was just having one. I get to  
19 meet the surgeon or the doctor that will take care of Katelyn after she's born and I say, "You know,  
20 I'm excited about having twins. I'm excited about having a Downs Syndrome child. I'm not worried  
21 about it." He still took the time to explain to me that Katie Beckett would insist that she receive the

1 same level of care as my other child regardless of my opinion or what I wanted to do. And I thought,  
2 “Wow, that’s great.” There’s a medical profession and there’s a society here that’s looking out for  
3 children with needs, even if I was a lousy parent. So, what’s happening right now is not true to the  
4 purpose of Katie Beckett.

5 *HEIDI McDOWELL:* Billie Warnock?

6 *BILLIE WARNOCK:* Hi. My name is Billie Warnock. W-A-R-N-O-C-K. And I am the  
7 mother of an eight (8) year old child who has Asperger’s and ADHD, and probably a mental illness.  
8 We don’t know yet. He’s spent time in a psych ward or psych unit at St. Alphonsus. He’s been on  
9 Katie Beckett for three or four years now, and he’s a very difficult child. He has IBI in the school  
10 system because he can’t function in the school system without an IBI. And he has IBI after school  
11 because he’s very, very aggressive. And he needs it. Our family cannot function as a unit without  
12 our son having IBI. And we have insurance. We have great insurance. Our insurance covers 90% of  
13 everything. He’s on over \$1,000 worth of medication and our insurance covers 90% of all that stuff.  
14 But it does not cover IBI therapy. It covers his OT. He does have OT, and it does cover his OT, but  
15 it’s covered as I think 60% of that. So, and you know, I work two jobs. My husband works one.  
16 And we look great financially, but I mean when they take into consideration all our bills. You know,  
17 I have student loans. We pay daycare for a younger child. My daughter’s going to college next year.  
18 So we don’t have any extra money to pay. I mean, we would pay 4½% of our income, but we don’t  
19 have 4½%. My husband is a construction worker. He’s a sheet metal worker. He’s a journeyman.  
20 But he didn’t work the first month and a half of the year. So if they take our income from last year,  
21 you know, we made good money last year, but the first month and a half we wouldn’t have been able

1 to pay the premium because we wouldn't have had the money. It would have been paying the  
2 premium, or our mortgage, or our daycare which we're obligated to pay or we lose our son's daycare,  
3 and our son's been in daycare since he was a year old and he's five (5) now, and we can't lose our  
4 son's daycare because then he loses his spot in his school because that's where he goes to school at.  
5 So that's not a position that we want either. So, I mean, this would hurt us in many aspects of our  
6 lives. And I just think the total income thing is not a good way to go about it because, you know, it's  
7 about economy. And we might look good on paper, but if they don't take into consideration all of our  
8 bills. I mean, I'm educated. I have an education, but I also have a lot of student loans I have to pay  
9 back. And we pay, you know, \$400 a month in daycare, which you know, those two things are  
10 \$1,000. You know, and our mortgage is over a \$1,000. You know, that's why I'm working two jobs.  
11 Just to pay those. You know, and my husband works, but he might get laid off. You know, he might  
12 work two weeks out of the month. You know, he might work two days out of the week. And they  
13 don't consider that. It's really hard to base it on an income when you don't know what the income's  
14 going to be. You know, and a flat fee we'd be okay with because then we can base, I mean we know  
15 what we're going to pay. We can plan it out. Like our mortgage, we know what our mortgage is  
16 going to be. We can plan for the mortgage, but we can't plan for something like that if he's going to  
17 be laid off. So, that's all I have to say. Thank you.

18 *HEIDI McDOWELL:* Thank you everyone for coming and thank you for providing your  
19 testimony. I'm just going to read the closing statement and then we can all be out of here.

20 *CLOSING STATEMENT*

21 This hearing, having been called, commenced at 5:00 p.m., and it is now 7:55 p.m., and is

1 now closed. The record, together with the exhibits, will be transmitted by me to the Administrative  
2 Procedures Section of the Department of Health and Welfare. Anyone wishing to submit further  
3 comments should address them in writing to: Tamara Prissack, Department of Health and Welfare,  
4 Administrative Procedures Section, 450 West State Street – 10<sup>th</sup> Floor, P.O. Box 83720, Boise, Idaho  
5 83720-0036. All written comments must be received or personally delivered to the Administrative  
6 Procedure Section by July 22<sup>nd</sup>, 2009. (*END TAPE 2, SIDE B*)

7  
8 **CERTIFICATION OF TRANSCRIPTION**

9 The undersigned does hereby certify that she correctly and accurately transcribed and typed  
10 the above transcription from the recording of the public hearing to the best of her ability as  
11 provided on three (2) microcassette tapes. Said public hearing took place in Caldwell, Idaho before  
12 before the public hearing facilitator, Heidi McDowell.

13 Dated and certified this 10<sup>th</sup> day of August, 2009.

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16 \_\_\_\_\_  
17 Tamara L. Swanson